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MICHAEL G. WILDING BSc Hons

EXPERIENCES OF LIVING WITH TYPE 1 DIABETES:
PSYCHOLOGICAL DISTRESS AND CLINICAL
IMPLICATIONS

Section A: Psychological distress and living with type 1
diabetes: A review of the literature

Word Count: 7960 (134)

Section B: Exploring the lived experiences of adults with type 1
diabetes: Psychological distress and implications for practice

Word Count: 7932 (436)

Overall Word Count: 15892 (570)

A thesis submitted in partial fulfilment of the requirements of
Canterbury Christ Church University for the degree of
Doctor of Clinical Psychology

APRIL 2015

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Doctorate in Clinical Psychology (D.Clin.Psychol.)

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SUBMISSION DATE

28/08/2015

OVERALL WORD COUNT

15892 (570)

Acknowledgements

Firstly I would like to extend my thanks to the people who gave up their time to meet with me and to share their experiences in the way that they did. I feel honoured and deeply touched to have heard your stories and to have the opportunity to share your experiences as part of this research. I also wish to thank the diabetes teams for your assistance with the project, the sharing of your ideas and your help with recruitment.

To Dr Angela Busuttil; thank you for your support, the sharing of your vast experience and your enthusiasm about what this research could achieve. Thank you to Prof Paul Camic for your guidance and thoughtful feedback throughout the research process. A special thank you is also reserved for the Salomons library staff for their continued support and availability.

Thank you as always to my Mum, Dad and sister Emma for your love and support, for always listening to my frustrations and offering me helpful advice.

Finally, thank you to my partner Juliet, for always believing in me, even when I found it hard to believe in myself.

Summary of the MRP portfolio

Section A is a review of the literature concerning diabetes related psychological distress and the impact this has for both individuals living with type 1 diabetes and health professionals. Studies investigating the relationship between diabetes related distress and various factors are examined, alongside studies evaluating the effectiveness of psychosocial interventions aimed at reducing diabetes related distress in practice. Limitations of the literature and suggestions for further research are discussed alongside implications for clinical practice.

Section B explores the experiences of adults living with type 1 diabetes using interpretative phenomenological analysis. Eight participants completed a semi-structured interview and the master and sub themes that emerged from these discussions are considered with reference to prior research. The implications of the findings for future research and practice are also discussed.

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MICHAEL G. WILDING BSc Hons

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Abstract

Background. Previous research suggests that people living with diabetes are as much as two-three times more likely to experience mental health difficulties compared with the general population. However, evidence is emerging that many of these difficulties may in fact be a direct result of feeling distressed about living with a complicated and stressful chronic health condition and not necessarily resultant from co-morbid psychiatric illness. These experiences are known by the term diabetes related distress. Recent studies have demonstrated that high numbers of people living with diabetes across the world report experiences of diabetes related distress, but as yet there exists no systematic review of the literature on this subject for people living with type 1 diabetes.

Aims. This review aimed to provide an overview of the recent literature concerning diabetes related psychological distress and consider the impact this has for both individuals living with type 1 diabetes and health professionals, within a biopsychosocial framework.

Method. The databases PsycINFO, MEDLINE and Web of Science were searched using the following terms: “Diabetes” OR “T1D” OR “IDDM” AND “psychological distress” OR “emotional distress”. Peer reviewed studies including; correlational studies exploring the associations between diabetes related distress and other factors, qualitative studies exploring peoples experiences of diabetes related distress and studies evaluating psychosocial interventions for diabetes related distress were identified and reviewed. References and citations were also checked for further relevant studies.

Results. Studies identified associations between diabetes related distress and poor management of the condition, alongside other factors such as: experiences of severe low blood sugar, level of satisfaction with healthcare support, and younger age. Group psychosocial interventions such as mindfulness based cognitive therapy, facilitated peer

support, and psycho-education appeared particularly effective at reducing diabetes related distress. Emerging evidence also suggests that individual psychological therapy within a mental health context may not be effective at reducing distress related to living with diabetes.

Conclusion. Diabetes related psychological distress is a complex phenomenon which potentially interrelates with various other psychological, biological and social factors across the lifespan. Studies are beginning to consider this concept for people living with type 1 diabetes alongside interventions which may be helpful. Despite this, further research and awareness of diabetes related distress in practice is needed.

Keywords: Type 1 Diabetes, Psychological Distress, Depression, Review

Introduction

Type one diabetes (T1D) is a chronic autoimmune disease culminating in the destruction of insulin secreting beta (β) cells in the pancreas (Bluestone, Herold, & Eisenbarth, 2010; Todd, 2010). Insulin is a hormone utilised in the metabolism of carbohydrates and lipids following digestion or release from storage, which results in elevated levels of glucose in the bloodstream (Randle, Garland, Hales, & Newsholme, 1963). Insulin operates by facilitating the uptake of glucose from the blood to the muscles for immediate use as energy, or fat and liver cells to become stored deposits (Peyrot, McMurry Jr, & Kruger, 1999). In healthy individuals the regulation of blood glucose involving insulin is homeostatic, with insulin being released from the pancreas when blood glucose levels become elevated (Matthews et al., 1985). In T1D the absence of insulin results in higher than optimum amounts of glucose in blood plasma known as hyperglycaemia (Giugliano, Ceriello, & Esposito, 2008).

Biomedical effects of type 1 diabetes

Hyperglycaemia can lead to acute physiological difficulties including fatigue, increased thirst and urination, headaches, dehydration and compromised immune functioning leading to increased risk of infection (Eastman, Johnson, Silverstein, Spillar, & McCallum, 1983; Montori, Bistrian, & McMahon, 2002). High blood glucose levels can also affect mood and decrease cognitive performance (Cox et al., 2005; Sommerfield, Deary, & Frier, 2004). Left untreated or when co-occurring with other acute illness, hyperglycaemia can quickly progress to dangerous states such as diabetic ketoacidosis (DKA), which are associated with multiple additional difficulties and a high risk of death (Kitabchi, Umpierrez, Miles, & Fisher, 2009).

Sustained hyperglycaemia over time can also lead to additional health complications. Long term blood glucose levels are monitored by testing glycosylated haemoglobin (HbA_{1c}) as part of diabetes management. Higher HbA_{1c} values increase the risk of complications (Nathan, 2014). However, only 26% of people with T1D in the UK have HbA_{1c} values in the recommended range, and subsequently diabetes¹ is the leading cause of blindness in working age adults and a direct contributor to cardiovascular disease, stroke, limb amputations, neuropathy and kidney failure (Diabetes UK, 2013).

To achieve optimal glycaemic control, people living with T1D are required to regularly administer exogenous insulin via injection for the remainder of their lives (Atkinson, Eisenbarth, & Michels, 2014). This forms part of ongoing blood glucose management as a component of a multifaceted behavioural and treatment regime (Shrivastava, Shrivastava, & Ramasamy, 2013).

In healthy individuals when blood sugar levels decrease the endogenous release of insulin is halted and stored glucose is released in response (Quesada, Tudurí, Ripoll, & Nadal, 2008). When treating T1D administering insulin can result in blood glucose levels decreasing even when below the optimum range (hypoglycaemia). Common symptoms of hypoglycaemia include autonomic responses such as sweating, tremor and increased heart

¹ Type two diabetes (T2D) and T1D are the two most common sub types of diabetes. They are often referred to collectively (alongside less common sub types) as 'diabetes' or 'diabetes mellitus' (World Health Organization, 2006). Despite this the pathogenesis (and subsequent treatment) of T1D differs significantly from that of T2D. The immune-associated destruction of pancreatic β cells present in T1D is not a feature in the development of T2D (Cnop et al., 2005). T2D is thought to be caused by a combination of age, lifestyle and genetic factors (Lindström et al., 2006). In T2D insulin is still produced by β cells but it is not utilised effectively due to the cells of the body becoming resistant to insulin activity (Alberti & Zimmet, 1998). Without treatment, both T1 and T2 diabetes result in hyperglycaemia albeit due to differing aetiology.

rate, often accompanied by feelings of anxiety. Furthermore, direct glucose deprivation to the brain causes neuroglycopenic symptoms including confusion, drowsiness and difficulties speaking or concentrating (Hepburn et al., 1991). If hypoglycaemia is not treated by ingesting carbohydrates, it can progress to coma and then death (Cryer, 2007). Attempting to control a metabolic process with a combination of medicine and behaviour is incredibly challenging. Subsequently it is often difficult for people living with diabetes to achieve optimal glycaemic control (Ali et al., 2013; Diabetes UK, 2013).

Psychosocial implications of living with type 1 diabetes

The biopsychosocial model of health and illness theorises that understanding the full impact that living with an illness is impossible, unless it is considered in terms of its biological, psychological and social dimensions (Engel, 1977). Applying the biopsychosocial model to managing T1D expands the viewpoint further than simply adhering to a behaviour and treatment regime. Peyrot et al., (1999) examined the interaction between biological and psychosocial determinants of diabetes control. They found that whilst treatment regime compliance was an important mediating factor, glycaemic control in T1D is more responsive to psychosocial factors including; education, marital status, positive coping styles, and levels of emotional distress compared to T2D.

Living with diabetes can introduce a number of social challenges. A recent review of the literature by Schabert, Browne, Mosely, and Speight (2013) concluded that despite the fact the general public widely believe that diabetes is not a stigmatised condition, many people living with diabetes report feeling stigmatised, judged and monitored by others. Many people living with T1D describe experiences of discrimination in the workplace (Petrides et al., 1995) and many health professionals working in diabetes care report

perceived social discrimination against patients (Holt et al., 2013). Family members of people living with diabetes often also experience a negative impact on their lives including: elevated distress, experiencing diabetes as a burden and feeling unable to help the family member concerned (Kovacs Burns et al., 2013).

The complex and continuous nature of attempting to manage diabetes day to day is considered highly psychologically demanding (Cox & Gonder-Frederick, 1992), and related psychological sequelae are commonly reported. Compared with the general population, people living with diabetes are up to 40% more likely to report elevated levels of anxiety, with rates of anxiety disorders 14% more common (Grigsby, Anderson, Freedland, Clouse, & Lustman, 2002). Recent meta-analyses estimate that people living with diabetes are twice as likely to experience depression compared to people without (Anderson, Freedland, Clouse, & Lustman, 2001), with people living with T1D as much as three times more likely (Roy & Lloyd, 2012). A meta-analytic review of the literature by Lustman et al., (2000) has also linked depression with hyperglycaemia for people living with both T1 and T2 diabetes.

However, emerging research in diabetes suggests these figures must be interpreted with caution. Fisher, Gonzalez, and Polonsky (2014) note that historic studies investigating the relationships between diabetes and depression (many included in the meta-analyses cited above) report inconsistent and contradictory findings. They suggest that taking a symptom based approach to quantifying emotional distress and depressive symptoms (often using traditional self-report measures without considering causes or content of symptoms), does not allow for the inclusion of the context of living with diabetes and its subsequent impact on these variables. They conclude that this has resulted in a failure to consistently define and measure depression across previous research studies in relation to diabetes.

Diabetes related psychological distress

Gonzalez, Fisher, and Polonsky (2011) argue that many emotional difficulties reported by people living with diabetes are labelled as co-morbid psychiatric disorders such as depression, when they may be better understood as reasonable feelings of distress about living with a health condition that is hard to manage, complicated and stressful. These experiences have been termed diabetes related psychological distress² and are defined by Strandberg, Graue, Wentzel-Larsen, Peyrot, and Rokne (2014) as:

“A range of emotional responses and reactions to life with diabetes, especially those related to the treatment regimen and self-care demands. It is part of a person's experience of managing diabetes and its treatment in the social context of family and health-care personnel” (p. 175).

People across the world have reported experiencing diabetes related distress. The recent diabetes attitudes wishes and needs (DAWN; Skovlund & Peyrot, 2005) and subsequent DAWN2 studies (Peyrot et al., 2013) involved nearly 15,000 people living with both T1 and T2 diabetes, a sample of their families and over 8,500 health professionals from 17 countries. The studies, reported across multiple papers, found that nearly 75% of people living with diabetes who were surveyed reported experiencing psychological distress related to one or more domains of their diabetes management (Skovlund & Peyrot, 2005). In addition, 46% reported clinically significant levels of diabetes related distress, which is likely to seriously impact upon functioning and well-being (Nicolucci et al., 2013). Diabetes

² Also referred to as diabetes specific/related emotional distress, diabetes specific/related distress, diabetes distress or DD.

related distress is also described by healthcare professionals as having a negative impact on people's management of diabetes (Peyrot et al., 2005).

Importance of understanding diabetes related distress

van Bastelaar et al. (2010) investigated the relationship of diabetes related distress to both depression and HbA_{1c} values for people living with both T1 and T2 diabetes. They found that diabetes related distress was an important mediator variable between both of these factors. This suggests not only that diabetes related distress may account for the presence of depressive symptoms using self-report measures, but also that it could potentially influence diabetes clinical outcomes such as glycaemic control. Furthermore, research by Lloyd, Pambianco, and Orchard (2010) found strong correlations between diabetes related distress and depressive symptoms for people living with T1D independent of other potential covariates including gender, diabetes duration and the presence of additional complications. Self-report measures for diabetes related distress have also been demonstrated to more accurately indicate the presence of sub-clinical depression, clinical depression and diabetes related distress when compared with measures of depression alone (Hermanns, Kulzer, Krichbaum, Kubiak, & Haak, 2006).

These findings are consistent with the arguments of Fisher et al. (2014) that diabetes related distress may account for depressive symptoms on self-report instruments, leading to the over diagnosis of depression by diabetes healthcare professionals. This lack of clarity has been described as promoting the use of interventions in clinical practice aimed at reducing depressive symptoms that do not adequately address an individual's distress related to living with diabetes (Esbitt, Tanenbaum, & Gonzalez, 2013).

Not providing appropriate support for diabetes related distress could have wide ranging implications. There were an estimated 366 million people living with diabetes

worldwide in the year 2000; this is predicted to increase to 552 million by the year 2030 (Whiting, Guariguata, Weil, & Shaw, 2011). People living with T1D constitute approximately 10% of this number (Diabetes UK, 2012), making them a significant minority within this group. Treating T1D cost the UK NHS £1.9bn in 2010/11, with half of that figure spent treating potentially avoidable health complications resultant from sub-optimal glycaemic control. Without action this figure is predicted to rise to £4.2bn (with £2.4bn spent on complications) by 2035/36 (Hex, Bartlett, Wright, Taylor, & Varley, 2012). Additional health complications related to poorly managed diabetes have also been shown to have a significant negative impact on an individual's perceived quality of life (QoL; Rubin & Peyrot, 1999). The associated costs (both economic and related to individual well-being) of poorly managed diabetes, mean that understanding ways to reduce its negative impact is considered a key ongoing public health issue (American Diabetes Association, 2013; Venkat Narayan, Gregg, Fagot-Campagna, Engelgau, & Vinicor, 2000). Diabetes related distress has been shown to be a significant mediator variable in glycaemic control for people living with T1D (van Bastelaar et al., 2010), and could be a key piece of the puzzle in the management of this serious and often costly health condition.

For people living with diabetes, optimal glycaemic control significantly reduces the risk of developing serious and costly health complications (Nathan, 2014) and is also associated with improved health related quality of life (Rubin & Peyrot, 1999). Despite this, it is often difficult for people living with diabetes to achieve optimal glycaemic control (Ali et al., 2013; Diabetes UK, 2013) and diabetes related distress has been shown to be a negative influence on how people manage the condition (Lloyd et al., 2010; Peyrot et al., 1999; Peyrot et al., 2005; van Bastelaar et al., 2010). Further understanding of this phenomenon

could be vitally important both for improving the lives people living with T1D and increasing knowledge of healthcare professionals who work with them.

Methodology

Aims of review

The importance of further consolidating knowledge and understanding of diabetes related distress has been demonstrated in Egede and Dismuke's (2012) comprehensive review of the contemporary literature. However, the review focused solely on T2D and the author is unaware of an existing review of this nature for T1D. This review aims to provide a systematic overview of recent literature in order to answer the following questions:

- A) What is the impact of experiencing diabetes related psychological distress for people living with type 1 diabetes?
- B) What psychosocial interventions for diabetes related distress are available for healthcare professionals working with people living with type 1 diabetes?

Review process

The databases PsycINFO, MEDLINE and Web of Science were searched using the following terms:

“Diabetes” OR “T1D” OR “IDDM”³ AND “psychological distress” OR “emotional distress”⁴.

³ IDDM = Insulin Dependent Diabetes Mellitus.

⁴ The term “distress” was originally used in place of “psychological distress” OR “emotional distress”. However this combination of search terminology yielded too many results to be realistically included

Searches were restricted to peer reviewed journal articles published in English only. Searches were also limited to the years 2012-2015. 2012 was chosen as a start point as the first papers from the DAWN2 study began to emerge around this time (e.g. Holt et al., 2013; Kovacs Burns et al., 2013; Nicolucci et al., 2013; Peyrot et al., 2013) and was a definitive moment in establishing the prevalence of diabetes related distress across the world.

Inclusion criteria

Research studies were selected for inclusion when the sample consisted of participants living with T1D only, or people living with T1D in addition to other types of diabetes and when diabetes related distress was either a primary or secondary variable measured. In addition, qualitative studies considering psychological distress for people living with T1D were also included.

Article titles were screened for appropriateness before abstracts were read fully to identify papers to select for full text screening. Identified articles were then read in full before deciding about inclusion in the review.

Published reference lists all of full texts read were scanned for citations meeting the review inclusion criteria. If identified, abstracts were retrieved and the process above repeated to assess eligibility and/or inclusion. 15 articles were selected to be included in the review. Figure 1 outlines the selection process in further detail.

in a review of this nature. In addition many of the results were inappropriate (e.g. investigating neuronal distress pathways).

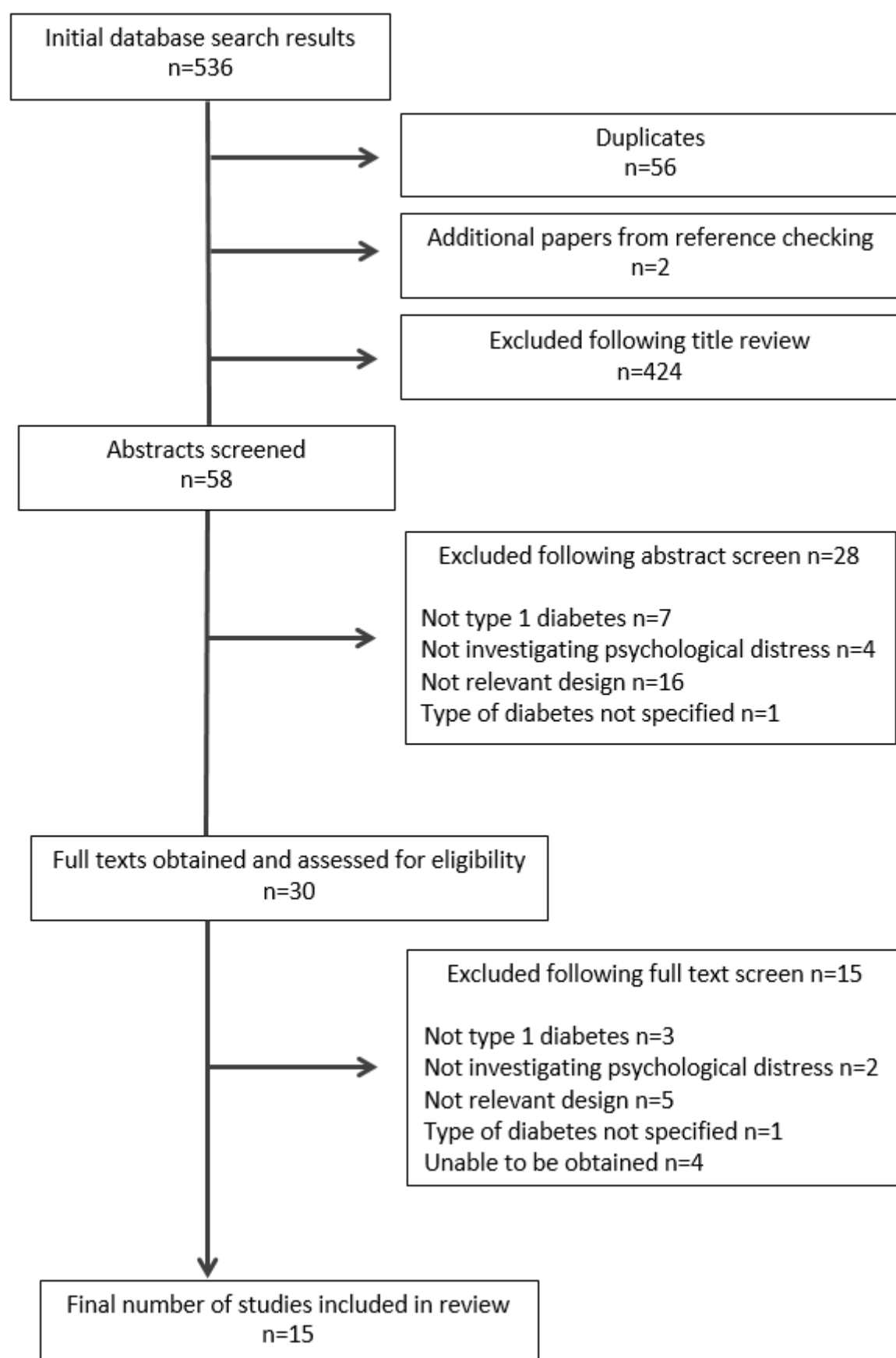


Figure 1. Study selection process flow diagram

Evaluation criteria

Articles included in the final review were critically evaluated with reference to appropriate criteria for good quality research. Randomised controlled trials (RCTs) were reviewed with reference to the Consolidated Standards of Reporting Trials (CONSORT) criteria (Schulz, Altman, & Moher, 2010). Other study designs were considered in light of the Critical Skills Appraisal Programme (CASP) criteria for good quality research relevant to the study design utilised (CASP, 2015). Qualitative studies were critiqued with reference to Elliott, Fischer, and Rennie's (1999) guidelines for the publication of qualitative research.

Many studies included in the review employed self-report instruments to measure a multitude of different variables. It is beyond the scope of this paper to evaluate the quality of all of these in detail. However the psychometric properties of self-report tools that were used to measure diabetes related psychological distress by 1 or more of the 15 review papers are presented in Appendix A.

Findings

Studies have been grouped together into four themes for reporting purposes, these are: 'Relationship between diabetes related distress and glycaemic control', 'relationship between diabetes related distress and other factors', 'mindfulness based psychological interventions' and 'other psychosocial interventions'. Table 1 provides an overview of studies included in the review.

Table 1. *Articles reviewed*

Author(s)/ Year	Sample Details	Intervention (if applicable)	Variables and Measures Used	Study Design	Key Reported Findings
Relationship between diabetes related distress and glycaemic control					
Reddy, Wilhelm, & Campbell (2013)	184 people living with diabetes (T1D n=51 & T2D n=133) Australia	Battery of self-report measures and structured interview	Diabetes related psychological distress (Problem Areas In Diabetes scale) General psychological distress (Kessler-10 item) Depressive Symptoms (Patient Health Questionnaire-9) Health Related QoL (Short-Form Health Survey) Past depressive history (Structured clinical interview with psychiatrist) Glycaemic control (HbA _{1c})	Cross-sectional design	Higher levels of diabetes related distress were significantly correlated with higher HbA _{1c} values. Diabetes related psychological distress was strongly associated with current depression and general psychological distress. Experiences of diabetes related distress were more common for people with a previous history of depression even in the absence of current depressive symptoms.
Scholes et al. (2013)	14 young people (aged 11-22) living with T1D USA	N/A	Participants placed into 'high' or 'low' HbA _{1c} groups based on previous results prior to the study. All participants completed the same open-ended interviews	Qualitative design. Analysed using inductive thematic approach	Many participants reported distress when dealing with health professionals who interacted in an authoritative way which was experienced as not understanding or helpful. Many friends or family members did not understand diabetes or were fearful of it, this was often experienced as increasing burden and distress about living with diabetes. However many participants also reported that friends and family often showed concern and helped to reduce distress.

					<p>Diagnosis was described as a distressing time by many participants and this distress often continued if people did not feel they were given adequate support or guidance by parents or health professionals.</p> <p>People with a high HbA_{1c} were more likely to report the experience of diagnosis as distressing, receiving less support from healthcare teams and families and were more likely to believe in the likelihood of a cure for diabetes in the future, than those with low HbA_{1c}.</p>
Zoffmann, Vistisen, & Due-Christensen (2014)	710 young adults (aged 18-35) living with T1D Denmark	Battery of self-report measures	Diabetes related distress (Problem Areas in Diabetes scale) Well-being (WHO-5 Well-being Index) Self-worth (Rosenberg's Self Esteem Scale) Support for autonomy from healthcare providers (Health Care Climate Questionnaire) Motivations for engaging in health behaviours (Treatment Self-Regulation Questionnaire) Perceived competence in managing diabetes (Perceived Competence in Diabetes Scale)	Cross-sectional design	<p>Higher well-being and perceived competence were correlated with lower HbA_{1c} values. Higher levels of motivation and lower diabetes related psychological distress were both correlated with lower HbA_{1c} levels. Health care climate was not found to be significantly correlated with HbA_{1c}. Clinically significant diabetes related distress was significantly more likely to be reported by participants with HbA_{1c} values above 8%, but was also common amongst individuals with HbA_{1c} values lower than 8%. Women were significantly more likely to report high levels of diabetes related psychological distress than men.</p>

			Glycaemic control (HbA _{1c} & number of diabetes related complications)		
Strandberg et al. (2014)	235 adults (aged 18-69) living with T1D Norway	Battery of self-report measures	Diabetes specific emotional distress (Diabetes Distress Scale & Problem Areas in Diabetes scale) Anxiety and Depression (Hospital Anxiety and Depression Scale) Well-being (WHO-5 Well-Being Index) Glycaemic control (HbA _{1c})	Cross-sectional design	Following regression analysis, significant associations between diabetes specific emotional distress and HbA _{1c} values were reported. There were no significant associations between depression, anxiety or overall well-being with HbA _{1c} levels.
Relationship between diabetes related distress and other factors					
Balfe et al. (2013)	35 young adults (aged 23-30) living with T1D Ireland	N/A	Semi-structured interviews	Qualitative design. Analysed using thematic approach	Diabetes related distress was commonly reported and was underpinned by many factors including; stigma/self-consciousness, difficulties managing diabetes day to day, fighting the health care system, restrictions and limitations, media representation of diabetes, worries about the future and concerns regarding pregnancy.
Kibbey et al. (2013)	86 young adults (aged 18-30) living with T1D from a region of social disadvantage Australia	Battery of self-report measures	Glycaemic control (Self-reported HbA _{1c}) Diabetes related distress (Problem Areas in Diabetes scale) Depression/Anxiety (Hospital Anxiety and Depression Scale) Illness perceptions (Brief Illness Perceptions Questionnaire)	Mixed-methods cross-sectional design	Participants reported feeling significantly more satisfied with their diabetes care if they were treated in tertiary care, had contact with an endocrinologist or nurse specialist within the last 6 months and were aware of their latest HbA _{1c} value. Those more satisfied with care experienced significantly lower levels of diabetes related distress, lower levels of anxiety and depression and lower HbA _{1c} .

			Enablers and barriers to accessing diabetes care (study-specific questionnaire) Optional free text responses		Diabetes related distress was higher in this age group than compared with the general population in adults in Australia. Responses to free text questions indicated that many participants experienced feelings of disempowerment, lack of acknowledgment as an individual, and disillusionment with ongoing efforts to control and manage diabetes.
Hendrieckx et al. (2014)	422 adults (mean age 37.5 years) living with T1D Australia	Battery of self-report measures	Assessments of hypoglaecemia: Self-reported severe hypoglaecemic episodes (derived from the Hypoglaecemia Awareness Questionnaire, HypoA-Q) Impaired awareness of hypoglaecemia (Gold score) Psychological measures: General emotional well-being (WHO-5 Well-being Index) Diabetes related distress (Problem Areas In Diabetes scale) Diabetes specific positive well-being (Well-being Questionnaire-28) Fear of hypoglycaemia (Hypoglaecemia Fear Survey)	Cross-sectional design	Participants who reported experiencing a severe hypoglaecemic episode in the previous 6 months were significantly more likely to experience increased fear of hypoglaecemia, greater diabetes related psychological distress and poorer general emotional well-being than those who had not experienced a severe episode of hypoglaecemia.
Stuckey et al. (2014)	8,596 adults living with diabetes (T1D)	N/A	Structured face to face, telephone and internet questions as part of larger survey.	Qualitative design. Emergent coding used to identify commonalities in	Negative psychosocial themes reported by participants included; feeling fearful and anxious, worry about hypos, concerns about the future complications, depression/negative

n=1,368 & T2D n=7,228) From 17 countries; Algeria, Canada, China, Denmark, France, Germany, India, Italy, Japan, Mexico, Netherlands, Poland, Russia, Spain, Turkey, UK and USA.				psychosocial experiences between countries.	mood, discrimination at work, and public misunderstanding about diabetes. Helpful psychosocial themes were; receiving support from compassionate healthcare professionals, family, friends and other people living with diabetes.
Mindfulness based psychological interventions					
van Son et al. (2013)	139 people living with diabetes (T1D n=42 & T2D n=97) with “low emotional wellbeing” (score > 13 on WHO-5 Well- being Index) Netherlands	Group mindfulness based cognitive therapy (MBCT)	Perceived stress (Perceived Stress Scale) Anxiety and depressive symptoms (Hospital Anxiety and Depression Scale) Mood (Profiles of Mood States) Diabetes specific distress (Problem Areas in Diabetes scale) Health related QoL (12-Item Short-Form Health Survey) Glycaemic control (HbA _{1c})	RCT cross-over design: MBCT intervention compared to treatment as usual (TAU) control group. Repeated measures (baseline, 4 and 8 weeks follow up).	MBCT intervention resulted in significant reductions in stress, depressive symptoms, and anxiety, alongside significant increases in QoL compared with TAU control group. No significant changes to either HbA _{1c} levels or diabetes related distress were found following MBCT intervention or TAU.
van Son et al. (2014)	139 people living with	Group mindfulness	Perceived stress (Perceived Stress Scale)	Follow up study for van Son et al. (2013).	Significant reductions in stress and anxiety combined with significant increases in QoL

	diabetes (T1D n=42 & T2D n=97) with “low emotional wellbeing” (score > 13 on WHO-5 Well-being Index)	based cognitive therapy (MBCT)	Anxiety and depressive symptoms (Hospital Anxiety and Depression Scale) Mood (Profiles of Mood States) Diabetes specific distress (Problem Areas in Diabetes scale) Health related QoL (12-Item Short-Form Health Survey) Glycaemic control (HbA _{1c})	RCT cross-over design: MBCT intervention compared to treatment as usual (TAU) control group. Repeated measures (original measures from 2013 study plus 6 month follow up from current study).	compared with TAU control group continued to be observed at 6 month follow up. The reported significant reduction in depressive symptoms found in the previous study was not maintained at 6 month follow up. No significant changes to either HbA _{1c} levels or diabetes related distress were found in either group at 6 month follow up.
	Netherlands				
Tovote et al. (2014)	94 people living with diabetes (T1D n=37 & T2D n=57) and depressive symptoms (score ≥ 14 on BDI-II)	Individual mindfulness based cognitive therapy (MBCT) or cognitive behavioural therapy (CBT)	Depressive symptoms (Beck Depression Inventory-II & Hamilton Depression Rating Scale) Anxiety (Generalized Anxiety Disorder 7) Well-being (Well-Being Index) Diabetes related distress (Problem Areas in Diabetes scale) Glycaemic control (HbA _{1c})	RCT: MBCT intervention compared to CBT intervention or waiting list control group. Repeated measures (baseline and 3 months post intervention)	Significant reductions in depressive symptoms, anxiety and diabetes related distress alongside increases in well-being were reported for participants in MBCT and CBT groups compared with waiting list controls. No significant effect was reported on HbA _{1c} values for participants in any group.
	Netherlands				
Other psychosocial interventions					
Due-Christensen et al. (2012)	54 people living with T1D (aged ≥ 21 diagnosed ≥ 1 year earlier)	Diabetes support group	Diabetes related distress (Problem Areas In Diabetes scale) Psychological distress and depressive symptoms (Symptom Checklist 90-R and WHO-5 Well-being Index) Glycaemic control (HbA _{1c})	Mixed methodological: Quasi-experimental, two-group (equal numbers of sample with HbA _{1c} above and below 8% split into ‘poor’ and	Both diabetes related distress, general psychological distress and depressive symptoms reduced significantly following intervention and were sustained at 6 and 12 month follow ups for people with both ‘good’ and ‘poor’ glycaemic control.
	Denmark				

			Qualitative data via focus group interviews	'good' groups) repeated measures design with pre and post intervention alongside 6 and 12 month follow-ups. Additional focus groups completed at final follow up.	No significant changes to HbA _{1c} levels or improvement in general well-being were reported following group intervention. Participants reported major benefits of group participation as feeling less alone and being intuitively understood by peers. Significant diabetes related distress was commonplace regardless of 'good' or 'poor' glycaemic control, although this was higher on average for individuals with higher HbA _{1c} levels.
Hopkins et al. (2012)	1,163 people living with T1D (mean age 41.5 years) United Kingdom	Structured group education programme in flexible insulin therapy	Biomedical: Glycaemic control (HbA _{1c}), weight, self-reported hypoglaecemia (hypo) awareness and severe hypo frequency. Psychological: Diabetes related distress (Problem Areas In Diabetes scale), mood (Hospital Anxiety and Depression Scale) and QoL (EuroQoL Group 5-Dimension Self-Report Questionnaire).	Repeated-measures design. Baseline and 12 month follow up.	Diabetes related distress, depressive symptoms and anxiety were all significantly reduced at 12 month follow up compared to baseline. Mean rates of severe hypoglaecemia were significantly reduced and hypo recognition significantly improved at follow up. Significant reductions in HbA _{1c} levels were found at 12 month follow up. No significant differences in QoL were observed at follow-up when compared with baseline.
Snoek et al. (2012)	1,567 people living with diabetes (T1D n= 691 & T2D n=876) age > 18 Multinational study involving:	Computer assisted monitoring of individuals psychological status and glycaemic control by clinicians at	Well-being (WHO-5 Well-being Index) Diabetes related distress (Problem Areas in Diabetes scale) Life Event Inventory (self-developed scale based on Social Readjustment Rating Scale)	Repeated-measures design. Baseline and 12 month follow up.	Discussing the psychological aspects of living with diabetes at routine appointments resulted in significant reductions on baseline scores of diabetes related distress as well as increased well-being at 12 month follow up. HbA _{1c} values were not significantly different from baseline at follow up.

	Croatia, Denmark, Germany, Ireland, Israel, Netherlands, Poland & UK	routine review appointment	Patient Agenda Questionnaire (self-selection of topic areas to discuss during appointment) Glycaemic control (HbA _{1c})		
Forlani et al. (2013)	60 people living with T1D (utilising intensive insulin treatment, all previously completed diabetes education programme) Italy	Structured diabetes group psychological support programme	Psychological distress (Psychological General Well-Being Index) Mood (Beck Depression Inventory & Self-Rating Anxiety Scale), Diabetes related quality of life (QoL) (Well-Being Enquiry for Diabetics) Health locus of control (Multidimensional Health Locus of Control) Glycaemic control (HbA _{1c})	Quasi-experimental, two-group (intervention vs. delayed start control), repeated measures design (baseline, and 6 months post- intervention).	Significant reductions in depressive mood, anxiety and psychological distress reported by intervention group at six month follow up. At follow up, significantly improved diabetes related QoL, alongside increased internal and reduced external locus of control reported by intervention group. Intervention group showed significant decreases in baseline HbA _{1c} values at follow up. No significant changes were found in control group for any variables measured.

Relationship between diabetes related distress and glycaemic control

Four studies considered the relationship between diabetes related psychological distress and glycaemic control as a primary outcome. Regression analyses completed by Reddy, Wilhelm, and Campbell (2013), found strong positive correlations between diabetes related psychological distress and HbA_{1c} values, consistent with previous research findings (e.g. Lloyd et al., 2010). Furthermore, there were significant associations between diabetes related distress and both current and previous reported experiences of depression. These findings support the ideas of Fisher et al., (2014) that diabetes related distress may account for high scores on self-report instruments for depression. However, the study sample included individuals living with both T1D and T2D. The results for people living with T1D were not reported independently therefore the possibility that findings may have been influenced by factors unique to living with T2D cannot be eliminated.

Scholes et al., (2013) explored experiences of young people living with T1D using open-ended interviews. Participants described a multitude of difficulties in the day to day management of diabetes and many believed that these were exacerbated by hormonal changes and/or diabetes related distress. These findings are consistent those of Reddy et al. (2013) that diabetes related distress is correlated with glycaemic control.

Participants with higher HbA_{1c} values were more likely to report the experience of diagnosis as distressing, and described receiving less help and support from family members, friends and healthcare professionals than those with low HbA_{1c}. Many also felt that healthcare providers had a propensity to be authoritarian in their dealings with them and rarely offered emotional support, which they believed would be beneficial. This suggests that the response of both healthcare professionals and the social system around an

individual may be important in terms of both alleviating distress and improving glycaemic control.

Some young people described relating to peers with diabetes as helpful and providing valuable learning, especially when interacting with others whom they perceived to have had good control over the condition. This indicates that peer support may also help to reduce distress and/or glycaemic control. The study used a sample of children and young adults only and suggests that young people may be more likely to experience diabetes related distress. The results are particularly applicable when considering the transition to adulthood and from paediatric to adult diabetes services. However it may be difficult to generalise the findings to adults living with T1D.

Strandberg et al., (2014) also considered the relationship between diabetes related psychological distress, anxiety, depression, and general well-being with HbA_{1c}. A sample of adults living with T1D completed a number of self-report instruments to measure the above phenomena, whilst HbA_{1c} was measured via blood test. Two measures of diabetes related distress were used, the Problem Areas in Diabetes Scale (PAID) and the Diabetes Distress Scale (DDS). Both were significantly associated with glycaemic control, with the regimen-related subscale of the DDS having the strongest relationship. In contrast, there were no significant associations between depression, anxiety or general well-being with HbA_{1c} levels.

The findings could suggest that diabetes related distress (particularly concerning diabetes self-care regimes) may influence an individual's glycaemic control more than many other psychosocial variables. This is strengthened by the concurrent use of two well validated self-report measures of diabetes related distress. The large sample size also increases the likelihood that results will be generalisable. These results are consistent with

other studies (e.g. Lloyd et al., 2010), but are contrary to the findings of Reddy et al. (2013) that concurrent depression was significantly associated with diabetes related distress.

Diabetes related psychological distress and its relationship to control of blood glucose levels was also investigated in a cross-sectional study by Zoffmann, Vistisen, and Due-Christensen (2014). Health records for a sample young adults living with T1D were screened for pre-existing data from standardised measures of psychosocial functioning and participants most recent HbA_{1c} values.

Results were adjusted for potentially confounding demographic variables and analysed using both linear and logistic regression models. All psychosocial variables apart from perceived level of autonomy were strongly associated with HbA_{1c}. High prevalence rates of diabetes related psychological distress were reported across the sample. Distress was significantly more likely to be reported by women rather than men and people with an HbA_{1c} value above 8%.

The results suggest that younger adults, particularly women and/or those with higher HbA_{1c} values are more likely to report greater amounts of diabetes related distress. The reported associations between diabetes related distress and glycaemic control are also consistent with both Reddy et al., (2013) and Lloyd et al., (2010). One strength of the study is the large sample size, which increases the generalisability of these findings, however these may be applicable to young adults only.

The three quantitative studies above all reported strong associations between diabetes related distress and glycaemic control. Despite this it is not possible to infer causality from these correlations. The cross-sectional nature of the research designs also makes it impossible to consider the direction of these relationships over time.

Relationship between diabetes related distress and other factors

Four papers considered the relationship between diabetes related psychological distress and other specific factors. Kibbey, Speight, Wong, Smith, and Teede (2013) surveyed a sample of Australian young adults using a study-specific questionnaire aimed at assessing enablers and barriers to care provision and the quality of current services. The authors measured the relationship between levels of satisfaction with diabetes care and depression/anxiety, diabetes related distress, and HbA_{1c}. A large number of the sample (40%) reported severe diabetes related psychological distress, which was significantly higher than among other age groups of adults living with diabetes surveyed in Australia. These results support the findings of Zoffmann et al., (2014) that young adults may be particularly susceptible to higher levels of diabetes related distress.

Those feeling more satisfied with their diabetes care experienced significantly lower levels of diabetes related distress, anxiety and depression and HbA_{1c} levels. On free text questions some participants reported feelings of disempowerment and lack of acknowledgment as an individual e.g. "I know myself better than anyone. Doctors read out of a book and expect that what they read is how it works. Well it's not, everyone is different" (pp. 881). Others described disillusionment with ongoing efforts to manage diabetes e.g. "Making an effort to improve HbA_{1c} but usually end up disappointed" (pp. 881). These findings suggest that experiences of good quality, person centered diabetes care can influence experiences of diabetes related distress and also glycaemic control and are consistent with the findings of Scholes et al., (2013). Due to the study design it is not possible to infer causality or the direction of these relationships over time. HbA_{1c} values in this study were self-reported and not obtained from clinical records or from blood test

results. This reduces the validity of this variable considerably given the potential of inaccurate reporting, especially given some participants qualitative accounts of feeling disappointed with their HbA_{1c} results.

Balfe et al., (2013) conducted semi-structured interviews with a sample of young adults in order to explore what was distressing about living with T1D. Diabetes related distress was widely reported by the sample and appeared to be related to a number of factors. These included: difficulties managing diabetes day to day, self-stigma/consciousness, concerns about the future (including specific concerns about pregnancy) and difficulties navigating and 'fighting' the healthcare system. Diabetes related distress appeared to be ameliorated when individuals had opportunities to discuss concerns with healthcare professionals and to attend peer support groups and education programmes. These findings corroborate those of Scholes et al. (2013) that peer support was viewed as particularly helpful and that many young people wanted more emotional support from their diabetes team.

The authors reported reaching data saturation during the interview process and provided examples of credibility checking with the participants, improving confidence in the validity of the findings. The study findings support the notion that early adulthood is a particularly distressing time for people living with T1D (Zoffmann et al., 2014), and that helpful responses from healthcare providers could go some way to reducing this (Kibbey et al., 2013). However the very specific age-range of the sample is also a significant limitation, reducing the generalisability of the results to the wider population of people living with T1D.

Hendrieckx et al., (2014) looked at episodes of severe hypoglycaemia and its potential associations with diabetes related distress, other psychosocial factors and HbA_{1c}

results for a sample of adults living with T1D. Results showed strong positive associations between episodes of severe hypoglaecemia and levels of diabetes related distress, diabetes specific wellbeing, general well-being and fear of hypoglaecemia. There were no associations between severe hypoglaecemia and HbA1c levels.

The results indicate that experiencing severe hypoglaecemia may increase diabetes related distress. The self-report measure used to record incidences of severe hypoglaecemia was not standardised (instead being created specifically for the study), and data provided was not confirmed (e.g. with blood glucose meter reading downloads). Therefore it is unclear how accurately participants were reporting these incidences, which presents the potential for over or under reporting of results. The inclusion of diabetes related distress as a secondary outcome means that any potential associations with other variables were not reported.

Stuckey et al., (2014) conducted large scale multinational qualitative research as part of the DAWN2 study. The sample included adults living with diabetes from 17 countries. The authors used a structured interview schedule conducted via telephone, the internet or in-person depending on the region. The interview focused on successes, challenges, and wishes for improvement in living with diabetes. Emergent coding was used to identify 23 categories related to psychosocial factors. These categories were then grouped together into two positive and two negative psychosocial themes.

The first negative theme was described as anxiety about hypoglaecemia and the possibility of developing diabetes related complications which is supported by findings from Hendrieckx et al., (2014) that experiences of severe hypoglaecemia can be distressing, and also corroborate previously reported associations between HbA_{1c} and diabetes related

distress, given that high HbA_{1c} values significantly increase the chance of developing complications (Nathan, 2014). The second was discrimination at work and misunderstanding by the general public about diabetes which is consistent with other research (e.g. Petrides et al., 1995; Schabert et al., 2013). One positive theme was described as maintaining a positive outlook and resilience, with the second being receiving psychosocial support from compassionate and caring friends, family, healthcare professionals, and others living with diabetes, which is consistent with many previously reported study findings (e.g. Balfe et al., 2013; Kibbey et al., 2013; Scholes et al., 2013).

The large sample size and the multinational nature of the research make these results highly generalisable and suggests that there are shared positive and negative psychosocial experiences of people living with diabetes across many different cultures and societies. However the large sample size has implications for the richness of the data with the structured interview not being conducive to detailed exploration of people's experiences. The sample size also resulted in a high volume of data, analysed by a large number of researchers. The authors reported high inter-rater reliability in coding and data analysis, but it does not rule out potential inconsistencies in approaches between different countries during data collection. This includes different translations of the interview schedule and how data may have been influenced by the use of multiple interview approaches (telephone, internet and face to face) in different regions. The sample consisted of a mix of T1D and T2D, as only a small percentage of the sample were people living with T1D it would be hard to confidently generalise these to this population in practice. Despite the limitations, the study nonetheless provides a convincing overview of peoples psychosocial experiences of living with diabetes.

Mindfulness based psychological interventions

Three studies reported the use of mindfulness based psychological interventions and the effect they had on diabetes related psychological distress. van Son et al., (2013) carried out an RCT with a sample of people living with diabetes and self-reported low emotional wellbeing. The study compared a group mindfulness based cognitive therapy (MBCT) intervention with a treatment as usual (TAU) control group.

Individuals in the MBCT group reported significant reductions in baseline levels of depressive symptoms, anxiety and perceived stress, as well as increased QoL compared with the TAU group at both four and eight week follow ups. No significant differences were found in levels of diabetes related psychological distress, or HbA_{1c} values between groups at any time point. Individuals in the MBCT group did show overall reductions in diabetes related distress compared with the control group but this was not statistically significant.

van Son et al., (2014) also reported the results of a six month follow up of the original (van Son et al., 2013) study. The study reported sustained reductions demonstrated in the original study for levels of anxiety and perceived stress for the intervention group in comparison with controls. However the previously reported significant reduction in depressive symptoms was not sustained at a six month follow up point, along with diabetes related distress and HbA_{1c} as per the previous study.

These results suggests that group MBCT may help alleviate anxiety, stress and QoL in long-term, but may not be as helpful for depression, diabetes related distress or glycaemic control. The study protocol is well-reported increasing confidence in the rigour of the randomisation process. One caveat is a large reported dropout rate from MBCT group (~26%) which may have exaggerated the treatment effect size.

Tovote et al. (2014) conducted an RCT comparing individual psychological interventions for people living with diabetes. A sample of adults living with both T1D and T2D were randomised to receive an MBCT intervention, a cognitive behavioural therapy (CBT) intervention or to a waiting list control group.

Statistically significant increases in reported well-being, alongside reductions in diabetes related distress, depressive symptoms and anxiety were reported by participants in the MBCT and CBT intervention groups post intervention unlike waiting list controls. No significant differences in HbA_{1c} values were found between groups. The reduction in diabetes related distress was slightly higher for the MBCT condition than the CBT condition, although both were statistically significant.

The results of Tovote et al., (2014) suggest that both individual CBT and MBCT may effectively reduce diabetes related distress. This is inconsistent with the findings of van Son et al., (2013, 2014), indicating that the individual nature of the intervention may be an important factor. This supports the findings of Kibbey et al., (2013) that receiving acknowledgement as an individual is an important component of good diabetes care. The study sample was relatively small, resulting in statistical analyses not being fully powered according to a priori calculations of 42 participants per condition. Furthermore, attrition rates were high for both intervention groups increasing the likelihood of overinflated effect sizes.

Both RCTs (van Son et al., 2013, 2014; Tovote et al., 2014) recruited a sample of adults living with both T1D and T2D. With the different subtypes of diabetes not being stratified separately in either study, it is difficult to confidently generalise these findings to the wider population of people living with T1D.

Other psychosocial interventions

Four studies investigated the use of psychosocial interventions and the effect that these may have on diabetes related distress. Due-Christensen, Zoffmann, Hommel, and Lau (2012) used a repeated measures design to investigate the effect of attending a diabetes support group over time for a sample of adults living with T1D. The support group was aimed at reducing the burden of diabetes related psychosocial problems and facilitated by four diabetes healthcare staff. Participants self-reported HbA_{1c} values were used to divide equal numbers of participants into groups based on 'good' or 'poor' glycaemic control (below or above 8% respectively).

Clinically significant diabetes related psychological distress was commonplace for individuals both in the 'good' and 'poor' glycaemic control groups, although this was higher on average for the 'poor' group. The authors reported significant reductions in both diabetes related and general psychological distress, as well as depressive symptoms following completion of the group intervention. These observed differences were sustained after both 6 and 12 months. In addition, participants completed a focus group after the final follow up in order to gather qualitative data about whether or not the group had been helpful in meeting their needs. Participants perceived the group to be beneficial in a number of ways. Many felt less alone and intuitively understood by their peers regarding their concerns about living with diabetes. Some described not feeling "fully capable" (pp. 253) of managing diabetes alongside concerns that others were coping better. When similar stories emerged through discussion, individuals described relief and surprise at hearing these shared experiences. This sharing and sense of togetherness in the support group was also described as encouraging more flexible attitudes to making beneficial changes to diabetes management routines.

The results suggest that people may experience high levels of diabetes related distress even if their glycaemic control is optimal, despite existing evidence of positive correlations between diabetes related distress and HbA_{1c} (Reddy et al., 2013; Strandberg et al., 2014; Zoffmann et al., 2014). HbA_{1c} values used to divide into 'good' and 'poor' groups alongside measuring change in glycaemic control were self-reported and not validated against clinical records, which may have reduced the validity of these results. The longitudinal data indicates that attending a diabetes support group may be of benefit across a large number of psychosocial indicators (including diabetes related distress) which can be sustained over significant time periods. However, the lack of a control group for the study also means that any change observed over time cannot be definitely attributed to a specific characteristic of the intervention used. Participants reported feeling better understood by peers and a sense of togetherness which may be important factors in the reduction of perceived distress. The importance placed on support from peers in groups is also consistent with findings of Balfe et al., (2013) and Scholes et al., (2013).

Hopkins et al., (2012) investigated the effect of attending the Dose Adjustment For Normal Eating (DAFNE; a structured education programme in flexible insulin dosage) on various biomedical and psychological outcomes. DAFNE is a five day programme focusing on measuring carbohydrates consumed when eating and calculating a corresponding amount of insulin. This insulin should then counteract the increase in blood glucose which occurs after digesting carbohydrates and aims to provide greater flexibility in what people can eat and when, in comparison with traditional insulin therapy (DAFNE study group, 2002).

A sample of adults living with T1D completed a battery of self-report measures at baseline and at a one year follow-up point. High levels of diabetes related psychological

distress were reported at baseline. Statistically significant improvements in HbA_{1c}, awareness and severity of hypoglaecemia, diabetes related distress, anxiety and depression were reported at one year follow-up. There were no significant differences in self-reported QoL observed at follow-up.

The study employed a large sample, and presented strong evidence that completing the DAFNE programme could result in improvements in glycaemic control alongside many psychological factors (including diabetes related distress) which are sustained over time. This is consistent with previous studies that suggest peer support groups can reduce diabetes related distress (e.g. Balfe et al., 2013; Due-Christensen et al., 2012; Scholes et al., 2013).

The reported reduction in both hypoglaecemic episodes and diabetes related distress also supports the findings of Hendrieckx et al., (2014) that severe hypoglaecemia is associated with diabetes related distress. However, there is a risk of overestimating the effect of attending the DAFNE programme, as only 55% of participants completed follow up data. This risk is further increased by the lack of a control group.

Snoek et al., (2012) measured the effect of introducing a computer assisted monitoring system to routine diabetes care. Participants' 'psychological status' was measured by completing self-report instruments in addition to latest HbA_{1c} test results. The scores were then included in a generated report, which was used by the individual and a clinician in order to guide discussion and agree outcomes during the routine diabetes outpatient appointments. Data were recorded at baseline and at a 12 month follow up. High prevalence rates of psychological distress were reported, with 17.6% of the sample reporting clinically significant scores. The authors found that discussing psychological aspects of living with diabetes prompted by the monitoring programme resulted in

significantly decreased levels of diabetes related distress and improved well-being at a 12 month follow up. There was no significant change observed in HbA_{1c} values over time.

The findings indicate that improvements in diabetes related distress and overall well-being (but not glycaemic control) can be achieved with a relatively simple intervention in routine practice. The study involved a large sample of 1,597 adults living with diabetes from many different countries' however only 891 were monitored at follow up. Therefore it may be possible that the observed reduction in distress could be due in part to high attrition rates. The sample also combined people living with T1D and T2D. As with previous studies that used this sampling method, it is difficult to be sure if the results are 100% applicable to people living with T1D.

Forlani et al., (2013) tested the effects of attending a structured psychological group support programme, for a sample of adults living with T1D. The group intervention was facilitated by a psychologist and focused on managing daily living with diabetes, with participants being split between an intervention and delayed start control group. Those participating in the psychological support group reported significant decreases in depressive symptoms, anxiety and HbA_{1c} levels compared to the control group at the six month follow up point. They also reported significant increases in both general and diabetes specific well-being (including diabetes related distress), and an increased internal and decreased external health locus of control. These results support other study findings (e.g. Balfe et al., 2013; Due-Christensen et al., 2012) that attending support groups help with the psychosocial aspects of managing diabetes as well as adding additional evidence that glycaemic control may also be improved. The study data suggests that self-efficacy (high internal locus of control) could also be an important component in promoting one or both of these

outcomes. Allocation into control or intervention groups was not randomised, with the control participants electing to postpone group attendance. This may have created a self-selection bias, with more enthusiastic individuals or those more in a position to make life changes accessing the intervention first. The studies high use of statistical testing also increases the likelihood of type 2 error.

Discussion

Implications for practice

The papers included in the review are consistent with the DAWN study findings that high numbers of people living with T1D experience diabetes related psychological distress. Emerging evidence suggests that this distress may be more prevalent in younger adults and particularly young women (e.g. Zoffmann et al., 2014), with those experiencing frequent severe hypoglaecemic episodes also more likely to report experiences of diabetes related distress (Hendrieckx et al., 2014).

Many studies reviewed reported strong positive correlations between diabetes related distress and glycaemic control. This was also consistent with other findings suggesting that clinically significant levels of diabetes related distress were more commonly reported by people with high HbA_{1c} values (e.g. Reddy et al., 2013). However diabetes related distress was still highly prevalent amongst people with optimal glycaemic control (Due-Christensen et al., 2012), which presents the potential for significant distress to exist as an unacknowledged difficulty for people who are achieving recommended HbA_{1c} results. There is also evidence that diabetes distress may have greater influence on glycaemic control than depression (Strandberg et al., 2014), particularly if this distress is related to difficulties with diabetes treatment regimes. This may be important to consider in practice

as the historic associations between living with diabetes and depression and its subsequent impact on glycaemic control have been the primary focus of much of the literature to date (Lustman et al., 2000; Anderson et al., 2001). The high prevalence rates of distress reported across age groups and irrespective of glycaemic control demonstrates the importance of awareness and screening in routine practice for diabetes related distress, an idea which is already well supported in paediatric diabetes care (Cameron, Northam, Ambler, & Daneman, 2007; Schwartz, Axelrad, Cline, & Anderson, 2011).

In terms of reducing diabetes related distress in practice, evidence suggests that simply discussing an individual's psychosocial experiences of living with diabetes in and of itself may help to reduce levels of distress (Snoek et al., 2012). An individual's perceived satisfaction with their quality of care has also been found to be associated with both diabetes related distress and glycaemic control (Kibbey et al., 2013). Qualitative data indicating the importance of response from healthcare staff further supports this. Responses considered positive and helpful included: consideration of the person as a valued individual, engaging in a non-authoritarian manner, having compassion and providing emotional support where possible (e.g. Balfe et al., 2013; Scholes et al., 2013; Stuckey et al., 2014).

Friends, family and particularly others living with T1D could also play an important role in reducing diabetes related distress. Some studies reported that individuals living with T1D highly valued feeling intuitively understood by peers, and that peer interactions helped to promote positive changes in diabetes management, which may contribute to reduced diabetes related distress (e.g. Due-Christensen et al., 2012; Scholes et al., 2013). This is consistent with the growing popularity of seeking peer support amongst people living with

diabetes through social media platforms such as Facebook (Greene, Choudhry, Kilabuk, & Shrank, 2011). Professionals may wish to consider recommending such online peer support networks and/or face to face facilitated support groups if available.

Specific group interventions have also proved effective. Attending a structured education programme in flexible insulin therapy was associated with sustained improvements in several biomedical and psychological outcomes including diabetes related distress and HbA_{1c} (Hopkins et al., 2012). Participation in a structured psychological group intervention also demonstrated similar improvements in glycaemic control, diabetes related distress, QoL and depressive symptoms (Forlani et al., 2013). Young adults have also reported the value of attending such programmes (Balfe et al., 2013). The importance of commissioning structured education programmes for T1D has been recognised by the National Institute for Health and Care Excellence (NICE), who advocate the inclusion of such groups in routine practice in the NHS wherever possible (NICE, 2011) and the results of this review further support those recommendations. Furthermore, group MBCT was demonstrated to result in sustained improvements in stress, QoL, anxiety, but not diabetes related distress or HbA_{1c} (van Son et al., 2013, 2014). Depressive symptoms also improved post intervention, but were not observed after six months. Whilst this intervention may offer some general benefits consistent with MBCT interventions in a psychiatric context (Hofmann, Sawyer, Witt, & Oh, 2010), the results of group MBCT do not compare favourably to other group interventions included in the review (e.g. Hopkins et al., 2012; Forlani et al., 2013) and may require further adaptation in order to prove effective at reducing diabetes specific difficulties.

Early evidence suggests that individual CBT or MBCT may be effective at improving diabetes related distress alongside anxiety, depressive symptoms and perceived well-being (Tovote et al., 2014). Whilst no changes were demonstrated for HbA_{1c} levels, psychosocial improvements in diabetes are considered important outcomes in their own right (Rubin & Peyrot, 1999), suggesting that individual CBT or MBCT may be helpful for individuals experiencing clinically significant levels of diabetes related distress.

Implications for future research

Some studies reviewed reported strong correlations between diabetes related distress and glycaemic control for people living with T1D (e.g. Reddy et al., 2013; Strandberg et al., 2014; Zoffmann et al., 2014). This is a potentially important relationship, but the cross-sectional nature of these studies mean that the direction of these relationships is yet to be determined and further longitudinal research investigating these associations is required. It is also impossible to infer causal relationships from these results. van Bastelaar et al., (2010) has previously demonstrated diabetes related distress to be an important mediator variable for glycaemic control in a sample of people living with both T1 and T2 diabetes. Additional investigation of this relationship in a sample of people living with T1D alone would help to develop understanding further.

Zoffmann et al., (2014) found that women were more likely to report diabetes related distress than men. This gender difference may be related to fact that in general, women are more likely to utilise healthcare services than men (Green & Pope, 1999) and that experiences of mental distress are likely to increase healthcare use (Koopmans & Lamers, 2007). Further exploration of gender differences amongst people living with T1D

may be required. It may be that distress in males living with T1D is less common or it may simply be less expressed.

Many studies measuring the effectiveness of interventions reported concurrent changes in both diabetes related distress and depressive symptoms (e.g Due-Christensen et al., 2012; Forlani et al., 2013; Hopkins et al., 2012; Tovote et al., 2014). This is consistent with diabetes related distress often appearing to account for depressive symptoms on self-report instruments (Lloyd et al., 2010; Esbitt et al., 2013). Fisher et al., (2014), propose that these two constructs may share a dimension they describe as “emotional distress” (pp. 769), which includes the context of diabetes alongside other life stressors and demands. They call for further research in order to end the “confusing tale” (pp. 764) that currently exists in the reporting of these experiences, which could lead to inappropriate interventions in clinical practice. Many of the studies included in the review did not explicitly acknowledge this potential overlap, indicating that additional investigation and consideration of this area is needed in order to avoid these pitfalls.

There is some indication that specific interventions can reduce diabetes related distress for people living with T1D. However there still remains a dearth of robust large scale studies investigating the effect of various interventions on experiences of diabetes related distress as a primary outcome. Of the two RCTs included in the review, one failed to achieve power and the other increased sample sizes by including a mixed sample of people living with both T1D and T2D. Indeed 6 of the 15 papers reviewed used the same sampling method. The lack of stratification or reporting of separate results for each subtype of diabetes makes extracting pertinent information from these studies difficult. Future studies utilising a sample containing more than one subtype of diabetes should aim to report results

for differing subtypes independently, in order to minimise the risk of invalid findings being applied in practice.

The review revealed a lack of recent well-evidenced psychosocial interventions for diabetes related distress for people living with T1D. Of the studies that did report an intervention (Due-Christensen et al., 2012; Hopkins et al., 2012; Snoek et al., 2012; Forlani et al., 2013; van Son et al., 2013, 2014; Tovote et al., 2014) most provided relatively few details on how to deliver the intervention in practice. A lack of detail in reporting how to deliver effective behavioural and psychosocial interventions for diabetes related distress in the extant literature has been previously noted (Peyrot & Rubin, 2007). In addition, the lack of consensus when defining distress and depressive symptoms for people living with diabetes (Esbitt et al., 2013), furthers concerns that ineffective interventions based on a limited evidence base are being offered to individuals who report symptoms of diabetes related distress in practice (Fisher et al., 2014). Further research that aims to provide a more detailed understanding of diabetes related distress, in order to inform the research and development of additional, effective psychosocial interventions is required.

Almost all of the studies employed the use of diabetes distress self-report measures to measure diabetes related distress. These are useful in generating prevalence rates and associations between distress and other variables. However they are less helpful at identifying in rich detail exactly what people find distressing about living with T1D, which might be useful in guiding future research and clinical interventions. Some studies have begun to consider this question by using semi-structured or open-ended interviews to yield rich qualitative data that compliments existing quantitative studies in T1D. However, to date theses have focused exclusively on children and/or young adults and do not cover the

experiences of working age or older adults living with T1D. In a recent literature review Ritholz, Beverly and Weinger (2011), noted that qualitative research methods in diabetes are becoming increasingly utilised and suggest that their use can address important questions that quantitative research cannot. Future qualitative research exploring the experiences of diabetes related distress for adults living with T1D could provide additional detail and understanding of this phenomenon, potentially complimenting data already provided by extant quantitative studies. This may in turn help to inform both the understanding of health professionals and further development of more effective psychosocial interventions for diabetes related distress for people living with T1D.

Conclusion

This review aimed to provide an overview of the recent literature concerning diabetes related psychological distress alongside potential implications for people living with T1D and health professionals. Consideration of the papers reviewed suggests that diabetes related psychological distress is a complex phenomenon which potentially interrelates with various other psychological, biological and social factors across the lifespan. Studies are beginning to consider this concept for people living with T1D alongside interventions which may be helpful. Despite this, further research and awareness of both diabetes related distress and effective psychosocial interventions in practice is needed.

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MICHAEL G. WILDING BSc Hons

Section B: Exploring the experiences of adults living with type 1 diabetes: Psychological distress and implications for practice

Word Count: 7932 (436)

A thesis submitted in partial fulfilment of the requirements of
Canterbury Christ Church University for the degree of
Doctor of Clinical Psychology

APRIL 2015

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Abstract

Background. Living with diabetes can present a number challenges for individuals. Managing diabetes day to day involves a complex medication and behavioural regime which interrelates with various important psychosocial factors. Previous research suggests that people living with diabetes are as much as two-three times more likely to experience mental health difficulties compared with the general population. However, evidence is emerging that many of these difficulties may in fact be a direct result of feeling distressed about living with a complicated and stressful chronic health condition and not necessarily resultant from co-morbid psychiatric illness. These experiences are known by the term diabetes related distress. To date psychosocial factors related to living with diabetes have mainly been explored quantitatively. However, qualitative approaches have increased in popularity in diabetes research in recent years and can add valuable and rich information to existing data from quantitative research. Extant qualitative research in diabetes has mainly focused on people living with type 2 diabetes or children with type 1 diabetes, leaving adults living with type 1 diabetes as a relatively under researched group.

Aims. The study aimed to answer the following research questions:

Primary: What are the lived experiences of adults with type 1 diabetes?

Secondary: What aspects of living with type 1 diabetes are experienced as distressing?

What are the potential implications for health services?

Method. Eight adults living with type 1 diabetes were interviewed about their experiences. Interviews were transcribed and analysed using interpretative phenomenological analysis.

Results. Six major themes emerged from participant's interviews. These were: Experiences of diagnosis, physical impact of type 1 diabetes, psychological impact of type 1 diabetes, social impact of type 1 diabetes, influence of healthcare teams and ways of coping. Example subthemes are: Feeling frustrated and restricted by treatment regimes, psychological and emotional distress, constant awareness and worry, impact on development and sense of self, stigma and lack of understanding from others, support from diabetes team and experiences of a simplistic view of diabetes.

Conclusion. Participants reported a wide variety of experiences related to the biological, psychological and social components of type 1 diabetes. Some of these were experienced as highly distressing whilst others were more easily managed. This was often dependent on individual differences and was not necessarily static over time. Further awareness of this in practice and a focus on diabetes and its treatment within the context of people's unique psychosocial circumstances is highly important in supporting people to reduce diabetes related distress, which can improve glycaemic control, health related quality of life and wellbeing

Keywords: Type 1 Diabetes, Psychological Distress, Depression, IPA, Qualitative

Introduction

Diabetes mellitus (diabetes) describes a number of chronic metabolic illnesses that are a significant and costly worldwide public health issue (Hex, Bartlett, Wright, Taylor, & Varley, 2012; Whiting, Guariguata, Weil, & Shaw, 2011). The most common subtypes of diabetes are type 2 (T2D) and type 1 (T1D; World Health Organization, 2006); current estimates suggest that approximately 36 million people live with T1D worldwide (Maahs et al., 2010). T1D typically develops in childhood (Gale, 2005) and has a distinct aetiology and recommended treatment when compared to other diabetes subtypes (Bluestone, Herold, & Eisenbarth, 2010).

Implications of living with type 1 diabetes

In T1D pancreatic beta (β) cells responsible for generating insulin are destroyed due to an autoimmune response (Todd, 2010). Insulin is a hormone involved in regulating blood glucose during metabolism of carbohydrates and fats (Randle, Garland, Hales, & Newsholme, 1963). The absence of endogenous insulin in T1D necessitates a lifetime of insulin replacement via injection with the aim of avoiding dangerously elevated blood glucose levels (hyperglycaemia; Atkinson, Eisenbarth, & Michels, 2014).

Hyperglycaemia causes excessive urination, headaches, severe dehydration, exhaustion and impaired immune response (Giugliano, Ceriello, & Esposito, 2008; Montori, Bistrian, & McMahon, 2002). Untreated individuals experiencing hyperglycaemia can rapidly deteriorate to potentially life threatening conditions such as diabetic ketoacidosis (DKA; Kitabchi, Umpierrez, Miles, & Fisher, 2009). Using insulin to achieve sustained glycaemic control also substantially reduces the risk of developing additional long-term

health complications (including neuropathy, retinopathy and nephropathy) that can result from prolonged periods of hyperglycaemia (Nathan, 2014).

However insulin therapy alone is not a panacea and forms part of an ongoing and complex self-care regime (Coyle, Francis, & Chapman, 2013). Injecting insulin can cause hypoglycaemia (low blood glucose levels), which results in various difficulties such as: shaking, sweating, confusion, drowsiness and disrupted cognitive functioning (Hepburn et al., 1991). If hypoglycaemia is not treated by consuming sugars then individuals risk brain failure and death (Cryer, 2007). In addition to medication use, many other factors can influence glycaemic control. These include: frequency of blood glucose testing, diet, physical activity, coping styles and problem solving skills (Shrivastava, Shrivastava, & Ramasamy, 2013).

Glycosylated haemoglobin (HbA_{1c}), an indicator of long-term glycaemic control, is measured as a routine clinical outcome in diabetes. National Institute for Health and Care Excellence (NICE; 2015) recommends an HbA_{1c} value below 7.5% for adults living with T1D. However, the complicated nature of managing diabetes means that 74% of people living with T1D in the UK are unable to achieve this (Diabetes UK, 2013). Consequently, diabetes is the primary cause of blindness in UK adults of working age and a significant contributory factor for serious health issues including limb amputations, kidney failure, cardiovascular disease and stroke.

A biopsychosocial view of type 1 diabetes

Applying the biopsychosocial model of illness (Engel, 1977) to T1D indicated that glycaemic control is heavily influenced by different psychosocial factors (Peyrot, McMurry Jr, & Kruger, 1999). Kibbey, Speight, Wong, Smith, and Teede (2013) also found that

acknowledgement of an individual's psychosocial circumstances by healthcare staff is perceived as important by people living with diabetes.

Living with T1D can impact on people's social networks. Large numbers of people living with T1D report experiencing social stigma and discrimination (Schabert, Browne, Mosely, & Speight, 2013) and family members of people living with diabetes also report that diabetes has a negative impact on daily living (Kovacs Burns et al., 2013).

There is also a well-documented link between living with diabetes and poorer psychological well-being. Anxiety disorders are significantly more common for people living with diabetes (Grigsby, Anderson, Freedland, Clouse, & Lustman, 2002). Depression is also estimated to be two to three times more prevalent for people living with T1D than the general population (Anderson, Freedland, Clouse, & Lustman, 2001; Roy & Lloyd, 2012) and is associated with poorer clinical outcomes (Lustman et al., 2000). Poorer outcomes for people living with diabetes who are experiencing depressive symptoms can be further understood by applying the health belief model (Janz & Becker, 1984). The model posits that the likelihood of engaging in health promoting behaviours (such as achieving optimal glycaemic control through self-management) is influenced by various factors including perceived self-efficacy and the perceived benefits to the individual. However, negative changes in an individual's psychosocial status (such as experiencing depressive symptoms) has been shown to affect perceptions of health related behaviour, resulting in decreased likelihood of engaging in health promoting behaviours (Rosenstock, 1974).

Depressive symptoms reported by people with T1D may be, however, more complex than first appears. Gonzalez, Fisher, and Polonsky (2011) posit that psychological distress reported by people living with diabetes is often misdiagnosed as depression even when the

distress is directly related to living with and managing diabetes. This diabetes related psychological distress has been demonstrated to account for the presence of depressive symptoms on self-report instruments (Lloyd, Pambianco, & Orchard, 2010). This may be because many screening tools for psychological distress take a symptom based approach, without consideration of their content or causes (Fisher, Gonzalez, & Polonsky, 2014).

The recent diabetes attitudes wishes and needs (DAWN and DAWN2) studies found that diabetes related distress is reported by almost 50% of people living with diabetes in 17 different countries (Nicolucci et al., 2013). With reports of clinically significant distress also more likely in young people compared with the rest of the population (Kibbey et al., 2013; Zoffmann, Vistisen, & Due-Christensen, 2014). This distress has also been found to have significant associations with glycaemic control (Strandberg, Graue, Wentzel-Larsen, Peyrot, & Rokne, 2014).

Psychosocial interventions for diabetes

The combination of physiological, psychological and social difficulties described above can have a significant impact on quality of life (QoL; Rubin & Peyrot, 1999) and research is beginning to consider psychosocial interventions that could help alleviate this.

Attending structured psychoeducational group programmes in flexible insulin adjustment results in significant improvements in glycaemic control, reduced frequency of hypoglaecemia and reduction in diabetes related distress, depressive symptoms and anxiety (Hopkins et al., 2012). Completion of a structured diabetes psychological support group programme also demonstrated comparable biomedical and psychological benefits, but without the same improvements in HbA_{1c} (Forlani et al., 2013). Facilitated peer support groups have also been evidenced to provide significant improvements in psychological

wellbeing over time (Due-Christensen, Zoffmann, Hommel, & Lau, 2012). In addition, those receiving individual cognitive behavioural therapy (CBT) or mindfulness based cognitive therapy (MBCT) also reported improvements in depressive symptoms and anxiety, but not diabetes related distress or glycaemic control (Tovote et al., 2014).

Despite some evidence concerning potentially helpful psychological interventions, the DAWN2 study found that many diabetes healthcare professionals do not feel able to provide adequate support for psychosocial issues (Holt et al., 2013). This is evident in UK, where approximately 85% of people living with diabetes do not have pre-determined access to psychological support (Trigwell et al., 2008). Where this does exist the majority of this support takes the form of referral to generic mental health services, who lack specialist knowledge of diabetes. This is confounded by the potential over diagnosis of depression amongst people living with diabetes resulting in these individuals potentially receiving inappropriate and/or harmful interventions in practice (Esbitt, Tanenbaum, & Gonzalez, 2013; Fisher et al., 2014).

Although there is a small number of research studies that outline potential psychosocial interventions for diabetes related distress for people living with T1D, there remains an overall paucity of evidence presenting effective psychosocial interventions in this area. In addition, extant studies often fail to give a detailed overview of the intervention used (Peyrot & Rubin, 2007), making it difficult to accurately apply these interventions in practice. When this is considered alongside inconsistencies in accurately defining and identifying diabetes related distress and depression for people living with T1D (Gonzalez et al., 2011), and the lack of confidence by health professionals that they can address these difficulties (Holt et al., 2013), this paints a concerning picture.

Qualitative research and diabetes

Gaining a more detailed understanding of people's experiences of living with T1D (including diabetes related distress) could potentially inform the future research and development of effective psychosocial interventions in this area. However, to date these phenomena have mostly been studied quantitatively (e.g. Nicolucci et al., 2013; Tovote et al., 2014).

In a recent literature review, Ritholz, Beverly, and Weinger (2011) note that qualitative research is becoming increasingly valued in behavioural diabetes research and consequently has seen a steady increase in recent years. The review highlighted that the majority of extant qualitative research in diabetes focuses on adults living with T2D, or children living with T1D. This may be indicative of the fact that T1D typically develops in early life (Gale, 2005), and that the majority of adults living with diabetes have a diagnosis of T2D (Maahs, West, Lawrence, & Mayer-Davis, 2010). However people living with T1D constitute 10% of people with a diagnosis of diabetes in the UK (Diabetes UK, 2012), making adults in this sub group a significant minority which is currently under researched. Qualitative studies have begun to investigate both experiences of living with T1D (Scholes et al., 2013) and experiences of distress for people living with T1D (Balfe et al., 2013) with samples of children and young people. These have yielded rich and useful results which complement existing quantitative data. However there remains a dearth of qualitative research exploring these same experiences in the population of adults living with T1D.

In light of the above, this study will aim to answer the following research questions:

Primary: What are the lived experiences of adults with T1D?

Secondary: What aspects of living with T1D are experienced as distressing?

What are the potential implications for health services?

Method

Participants

Eight people participated in the study. All met the following inclusion criteria:

- Aged 18 or older.
- Living with T1D for at least 1 year or longer.
- Receiving care from a diabetes team at one of three recruitment sites.

Additional demographic information about the study sample can be found in Table 1.

Table 1. *Participant demographic data*

	Age (years)	Gender	Ethnicity	Number of years living with T1D	Presence of complications
P1	23	Female	White British	11	No
P2	40	Female	White British	37	Yes
P3	25	Female	White British	14	No
P4	27	Male	White British	12	No
P5	34	Female	White British	27	Yes
P6	34	Male	White British	31	No
P7	25	Female	White British	20	No
P8	50	Male	White British	41	Yes
Mean	32	-	-	24	-

Recruitment

Participants were recruited from three hospital sites across two separate NHS healthcare trusts. An opportunity sampling method was used, with potential participants either responding to a recruitment poster (Appendix B), or contacting the author to opt in to the study after being provided with the participant information sheet (Appendix C) by a member of the diabetes team when they attended for routine outpatient appointments.

Potential participants were also offered the chance to win a £50 shopping voucher as an incentive for taking part in the study.

Design

The study employed a semi-structured interview design. Participants were interviewed about their experiences of living with T1D and their responses were analysed using interpretative phenomenological analysis (IPA; Smith, Flowers, & Larkin, 2009). The aim of IPA is to “reveal something of the experience” (p.3) of individuals involved. This is achieved by taking an idiographic approach to interpreting how an individual makes sense of personally significant phenomena within specific contexts. IPA was selected in order to allow for exploration of the different connotations that people living with T1D attach to their experiences. Other methodologies were considered, for example grounded theory (e.g. Glaser & Strauss, 2009) which would aim to generate a theory to explain the experience of diabetes related distress for adults living with T1D, and thematic analysis (e.g. Braun & Clarke, 2006), which aims to describe and categorise qualitative data into themes. However, as the phenomenon in question is currently under-researched in qualitative studies, a detailed and rich description and process of meaning making (such as would be provided by IPA) was considered to be a better fit for initially advancing knowledge in this area compared to other methods. In addition, the author was diagnosed with T1D in childhood and the double-hermeneutic nature of IPA was also considered the best way to incorporate the author’s personal knowledge and experience of T1D in a way that would be beneficial to the research.

Ethical considerations

The initial study proposal was approved by a university research review panel, a NHS research ethics committee review (Appendix D) and two local R&D departments (Appendix

E). The main ethical issues discussed during the review process concerned identifying protocols to support participants who potentially became distressed following interview, alongside ensuring informed consent and confidentiality upon reporting.

Procedure

Once recruited participants met with the researcher, informed consent to participate was taken (Appendix F), followed by the completion of a semi-structured interview which was audio recorded and followed by a debriefing. The interview schedule (Appendix G) was informed by a literature review and expert opinion provided by the author's two supervisors. A pilot interview was also completed with one person living with diabetes prior to commencing and their views incorporated. The interview schedule began by asking people to recall their experience of being diagnosed with T1D, in order to ascertain what meaning people attached it, given that diagnosis is often viewed as a significant and distressing experience (Skovlund & Peyrot, 2005). The questioning then asked people to consider how this meaning had changed over time based on their experiences, both now and in the past, before considering how people felt about living with diabetes in the future. The schedule aimed to cover general areas of living with T1D, with the semi-structured nature also allowing individuals experiences of distress to emerge through discussion, given that this is an often expected reaction to living with T1D and its treatment (Gonzalez et al., 2011). The original interview questions did not change as the study progressed, but the interviewer made additional inquiries about pertinent issues raised by participants, and would continue to discuss these in subsequent interviews. Interviews lasted between 35-99 minutes depending on the individual and their responses. No participants reported significant distress after the interview or felt the need to discuss the interview with the

diabetes team. All participants also wished to receive short summary report of results (Appendix H).

Data analysis

The recommendations of Smith et al., (2009) were used as an overview to guide the data analysis. Following completion of the interview, transcripts were transcribed verbatim by the author. Transcripts were then read through whilst listening to the audio recording in order to be immersed in the data. Transcripts were then read a second time, whilst initial areas of interest or significance were marked and noted. Finally texts were re-read and the author's interpretations of marked parts of the transcript were recorded by hand, and were then assigned initial themes, aiming to encapsulate the meaning of participant's words (see Appendix I for an example annotated transcript). Following this transcripts and themes were transferred to electronic format, and NVivo 10 computer software (QSR International, 2014) was used to examine divergence and convergence between participants' experiences. This allowed for the grouping of initial emergent themes into sub themes and later into overarching master themes (see Appendix J for an overview of them development).

Quality controls

To ensure quality, Elliott, Fischer, and Rennie's (1999) guidelines for qualitative research was applied during the study process. In order to assist with "owning one's perspective" (Elliott et al., 1999, p. 221), a colleague interviewed the author prior to data collection with the aim of increasing reflexivity by 'bracketing' their assumptions (Smith et al., 2009), see Appendix L for an interview transcript. The interview was based around 10 key elements of reflexive bracketing outlined by Ahern (1999); an overview of these is provided in Appendix K. These areas were also used to guide the process of continued self-

reflection and the keeping of a research diary throughout (see Appendix M for diary extracts).

In keeping with the recommendations of (Elliott et al., 1999) the analysis and results were also subject to various “credibility checks” (p. 222). Firstly, initial theme development was discussed with two separate research supervisors, both with experience of direct work with people living with diabetes. Interview transcripts were also read in full by one supervisor. Ideas and discrepancies were discussed and were used to inform and amend the analysis as necessary. In addition findings were further corroborated with feedback from participants who responded to the summary report (Appendix H). For example participant three reported: *‘I think you’ve focused in on all the massive bits’* and participant four said: *‘I think it covers a lot and has a lot of insight. It’s great!’*.

Results

Following data analysis, six master themes emerged. These are presented along with their component sub themes in Table 2 below. The themes are described below with example quotations so as to allow for “grounding in examples” (Elliot et al., 1999. p. 222) in the words of the participants’ themselves (additional examples for each theme can be found in appendix N).

Table 2. *Overview of master and sub themes.*

Master Theme	Sub Theme
Experiences of diagnosis	Process of diagnosis
	Reacting to diagnosis
	Adjustments and changes
Physical impact of T1D	Experiences of high blood glucose

	Challenges managing blood glucose
	Experiences of hypoglaecemia
	Feeling frustrated and restricted by treatment regimes
	Additional health complications
Psychological impact of T1D	Psychological and emotional distress
	Constant awareness and worry
	Impact on behaviour
	Impact on development and sense of self
Social impact of T1D	Perceived impact on others
	Help and support from others
	Stigma and lack of understanding from others
Influence of healthcare teams	Support from diabetes team
	Difficulties with diabetes team
	Attending carbohydrate counting courses
	Simplistic view of diabetes
Ways of coping	Discussing diabetes
	Technology
	Not thinking about or engaging with diabetes
	Accepting and engaging with diabetes
	Hope and positivity

Experiences of diagnosis

This master theme covers people's experiences of being diagnosed with T1D and the immediate impact on individuals and their family networks.

Process of diagnosis

Most people described being unwell before receiving a diagnosis and being admitted to hospital *'I was drinking loads and going to the toilet loads and all the normal symptoms, um Mum and Dad took me to the hospital nearby and, I got diagnosed'* (P2)⁵. For the majority this felt like a sudden shift *'I was straight in the doctors and on insulin within like six hours'* (P3) but others described the process taking longer due to symptoms being misdiagnosed. Whilst in hospital, many people received limited information about T1D and felt unprepared upon being discharged *'I wasn't really told, how to really manage it'* (P1).

Reacting to diagnosis

For some diagnosis triggered feelings of disbelief and denial *'I guess there was like, the classic sort of slight disbelief.'* (P4), whilst others were scared and upset *'It was a scary time.'* (P5). Those who had waited longer to receive a diagnosis experienced a sense of relief *'When I was first diagnosed it was more of a relief to know something was wrong'* (P7). Whilst people diagnosed before they were old enough to remember felt less distressed by the experience *'I haven't known any different which I think is probably easier'* (P2).

Adjustments and changes

Being diagnosed often resulted in significant changes for people that were difficult to manage *'I started off on two injections, then rapidly went on to four. So. Quite a lot to deal*

⁵ (Px) = participant number

with aged nine.' (P7). Most people felt that diagnosis also had a significant impact on their parents *'It was really really scary, scary times for my, uh for my parents actually'* (P8), as well as other family members *'It would have been hard for my brothers and sisters'* (P4).

However those who felt that diagnosis didn't result in drastic changes (for example someone with a sibling living with T1D), felt that adjusting was easier *'At home, the diet was set around my brother anyway so, there wasn't that much change (...)⁶ yeah, it was quite good because I just knew it, I knew what it was and it wasn't a scary thing'* (P3).

Physical impact of type 1 diabetes

Living with T1D has on a significant impact on people's physical wellbeing. This master theme encapsulates participants' experiences in relation to this.

Experiences of high blood glucose

When people experienced hyperglycaemia, this resulted in feeling very unwell *'When I've got high glucose I do feel crap'* (P4). This common occurrence was often accompanied by intense frustration and confusion surrounding the potential cause *'It can get frustrating, (...) especially if you don't know why it's quite so high, it's, you know quite a few of them I can't explain.'* (P2). Keeping blood sugar levels in a slightly high range was also a coping strategy used by many. This reduced uneasiness due to it minimising the risk of hypoglycaemia *'Thinking about it I probably just run high most of the time (...) it's probably more the fact that I'll just run high just to stop that risk of being low'* (P1).

Challenges managing blood glucose

Attempting to manage blood glucose levels day to day was experienced by almost all participants as complicated and draining *'It's hard work sometimes, really hard work'* (P6).

⁶ Material deleted for confidentiality or clarity

Many felt out of control and that blood glucose levels were not fully manageable despite their best efforts *'I've always gone up and down. Even when I eat the same thing, on the same day. My sugars go up and down.'* (P7). This was often exacerbated by a perceived lack of skills and knowledge in managing T1D *'I wasn't schooled in anything (...) There's no logic, it was all just like, hit and miss.'* (P4). Practice over time and learning skills such as carbohydrate counting appeared to increase people's confidence that they could cope *'And I got all these skills about carbohydrate counting and then I starting getting, like feeling better about it I think'* (P4). Furthermore, experiencing a prolonged period of stable blood glucose or a reduced HbA_{1c} value resulted in a strong sense of pride and achievement for many *'It's brilliant being able to just go, you know, I've got this absolutely f***king nailed [Laughs] This diabetes lark.'* (P6).

Experiences of hypoglaecemia

Experiencing mild hypoglaecemia was unpleasant and confusing for the majority of people *'Because I've been hypo I then feel rough for the rest of the day'* (P2). More severe hypoglaecemic episodes were experienced as very frightening *'I used to, um, be so scared of having a fit during the night'* (P5). Almost all participants described hypoglaecemia as having a noticeable impact on day to day life *'It does get annoying if you're low and then you can't go somewhere or do something because it's low and you have to wait for it to come back up'* (P2).

Feeling frustrated and restricted by treatment regimes

Feeling restricted by the requirements of diabetes treatment was an experience reported by many *'Not having a lie-in, for, at least 10 years where (...) you had to set your alarm for 8 o'clock and wake up and inject and then go back to sleep, and things like that'* (P3). People described a necessity for planning and effort to make it fit into everyday life

'And you have to plan, you can't just do something, straight off it just doesn't happen these days' (P8). The need to plan and consider decisions meant that many felt they were often preoccupied with things such as diet and bodily sensations *'I do have to be quite careful about what I'm eating or how I'm feeling'* (P1). Many described improvements in technology (such as insulin pumps) as helping alleviate restrictions, but there were still limits to what technology could do *'It's more of a hassle (...) when, the pump needs to be changed every 3 days.'* (P6).

Additional health complications

Some participants had developed diabetes related complications. Experiencing complications led to being even further restricted by diabetes *'I had a massive bleed in one of my eyes. Um. And I couldn't see out of that eye (...) for those five months, I completely lost my independence'* (P5). Developing complications was also a frightening and distressing experience *'It's scary losing your sight, losing one of your senses. You miss so much, you just, I got depressed. Um, just found life really difficult.'* (P5). For some developing complications triggered a change in focus such as a drive to improve control of diabetes *'up until that point I'd not seen any of the long term effects. (...) of actually having it. And at that point it was kind of a trigger point'* (P6), and for those with more severe complications it was difficult to focus on anything else *'Diabetes is all consuming to me now.'* (P8).

Psychological impact of type 1 diabetes

The psychological implications of living with T1D were widely discussed by participants and are explored within this master theme.

Psychological and emotional distress

Almost all of the participants reported experiencing distress related to living with diabetes at some point in their lives *'Because of everything that was going on it really*

affected my mood really negatively' (P1). Some felt that this was related to ongoing internal pressure *'The hardest thing I think has just been, the, yeah, that kind of psychological pressure that it's had on me.'* (P4), whilst others believed diabetes contributed to feeling depressed *'I know diabetics are more prone to getting depression and I do go through phases of it.'* (P5). During the interviews, discussing and acknowledging the emotional impact of diabetes was viewed as important *'It's not an easy thing to live with. (...) and being able to get that message across (...) Is important, I think.'* (P6), but was sometimes experienced as an upsetting thing to attempt to do *'It was difficult to verbalise my thoughts and feelings (...) I know from past experience talking about my diabetes in any depth would bring me to tears or make me really upset'* (P1). The impact of psychological distress was also not static and shifted over time *'The sort of negative stuff from the diabetes has got better. (...) it's not fixed'* (P4).

Constant awareness and worry

The majority of people felt that the continuous nature of managing and thinking about diabetes, irrespective of whatever else was happening in their lives, was a significant psychological burden *'You can't switch off from being a diabetic, you can't forget about it'* (P8). Many felt they were constantly worrying about their blood sugars, to the extent that it was often hard to be present and engaged with other activities *'I'm thinking about what's happening in my body and my brain, and (...) it's like then I've removed myself from, you know, the, the event that I'm in currently.'* (P4). Most people also worried about what might happen in the future, such as developing complications *'You've always got the thought of things could go wrong or the complications that could happen.'* (P2), or the potential impact on having children in the future *'Kids. Always on the forefront of my mind, because, (...) I just keep thinking if my diabetes isn't controlled, that can cause miscarriages, it can cause*

children to have disabilities, you know heart defects, everything' (P3). Experiencing these regular concerns about diabetes led to a sense of failure and fears that people were 'getting it wrong' with their diabetes care *'I got to a point (...) where I was like, it doesn't matter how hard I try, it's always going to be wrong, or there's always going to be something there that's going to get in the way' (P1).* These prolonged periods of worry and stress appeared to accumulate over time resulting in a significant impact on wellbeing *'It's this thing of it just wearing you down over time like a, yeah. All these tiny little moments where you have all these, uh, like problems because of the diabetes' (P4).*

Impact on behaviour

Many people felt that physical symptoms influenced their mood and behaviour *'I just get moody, I get irritable, um grumpy I think. (...) and I do put that down to, just how you feel with your diabetes, if you don't feel great then you feel grumpy' (P8).* This was usually experienced as outside of people's conscious control, but was often not interpreted by others in this way, leading to feelings of guilt and blame *'I was doing stuff that just wasn't, wasn't who I was, or who I am. (...) and I got really upset that I was being blamed for it as well, because it wasn't something that I could control.'* (P1). The need to think and plan when living with T1D meant that many people were often more careful about their behaviour as a result *'In a way I guess it's like, uh, it kind of keeps me, more inclined to be like regular, not boozing and stuff, like that.'* (P4). This also made it difficult to feel spontaneous and fun which was often overlooked or misinterpreted as being difficult by others *'I can't be so kind of "spontaneous" um, like the rest of the population can' (P8).*

Impact on development and sense of self

A large number of people felt upset and acutely aware of being different to others, particularly when growing up *'The main thing was being different, and not wanting to be*

different wanting to be the same as everybody else. Um, the why me? Scenario.' (P2). Many also experienced a period of 'rebellion' during adolescence, which was fuelled by fighting against diabetes, more responsibility and expectation to manage independently *'As I went through my teenage years, I rebelled. (...) I'd buy sweets on the way home, (...) Not do insulin for them. Um. Didn't test my blood sugars. Just really rebelled.'* (P5). Most people felt that becoming more mature meant that they started to prioritise diabetes more highly *'Growing up's helped. Hmm, and priorities changing. (...) I think diabetes has made me grow up a lot faster'* (P3), and that this helped to integrate diabetes into their sense of who they were as people *'Nowadays I just accept it's part of me'* (P2).

Social impact of type 1 diabetes

This master theme is comprised of sub themes related to people's experiences of living with T1D in the context of social situations and systems.

Perceived impact on others

All of the participants interviewed felt that diabetes often had a negative influence on relationships with others such as partners, family and colleagues *'It does affect relationships'* (P6). This left some feeling like a burden and often endeavouring to minimise the perceived impact on other people *'It's a lot to do with not putting other people out and thinking it's my condition and not anybody else's to deal with but, I know it does have a knock-on effect on other people'* (P2). Others experienced feelings of guilt *'I think about it and I feel like, oh I was such a nightmare, I feel so guilty'* (P4).

Help and support from others

Feeling supported by close family members (such as partners, siblings or parents) was experienced by most as extremely helpful *'With my Mum. (...) she was there when I was diagnosed. Um, and she's always supported me in everything. Really has, she's the only one*

that understands what I've been through.' (P5). Voicing and sharing worries and tasks involved in managing diabetes with others (such as house mates or work colleagues) also appeared to result in a feeling of normalisation and greater support *'Like, everyone kind of knows, is aware of it and it sort of just, present, and vocalised. That has made me, be more, I guess more active with it. (...) because it's, gives it like a sort of, normal, err, like feel to it'* (P4). However, some reported a dilemma between asking for help and wanting to feel independent *'Asking for help and accepting help is really difficult. But at the same time I really want it, and now I'm really aware, I still want them to go, you know, are you alright? So, yeah, balancing those two is, difficult.'* (P1). Some also felt that the understanding of diabetes amongst the general public has improved over time, which was experienced as a helpful change to their wider social systems *'I think people's knowledge has got a lot more.'* (P3).

Social stigma and lack of understanding from others

Despite improvements in knowledge and awareness, many people often felt stigmatised by others, such as difficulties when trying to do injections *'I kind of felt like I was a drug addict, (...) that's how they were treating me.'* (P7). The majority of people interviewed had a strong sense of often feeling alone with diabetes and that no one else truly understood *'You always feel like you're on your own and nobody else quite understands'* (P2). These feelings were often exacerbated by the unseen nature of T1D and that people were not always aware of how difficult and serious it could be, even when people looked 'normal' on the outside *'It's one of those (...) Unseen conditions, yeah. It's one of those things, where people just go "Oh, you look fine". Yeah, I really don't feel fine [laughs]. Um, you know, and people don't understand'* (P6). A large number of people also found it frustrating when people confused T1D with T2D, which appeared to happen

regularly *'Or I've had "oh, but you're not fat". Yeah I know! [Laughs] Cos I'm not type 2.*

There's no, understanding from, I think, members of the public and the hospital between the two differences' (P7).

Influence of healthcare teams

Diabetes teams and the wider health service appeared to play a significant role in people's experiences of living with T1D. Sub themes related to this are encapsulated within this master theme.

Support from diabetes team

A large number of people felt that on the whole the diabetes team was helpful and supportive *'Long story short. They're excellent' (P6)*. In particular people felt supported when trying to think about managing blood glucose *'They're not just handing it to you on a plate, they're making me kind of think and they're supporting me doing it' (P3)*. Others felt reassured that regular health checks were carried out *'The reassurance of the other tests that they do like the cholesterol' (P2)*, and also that the team were available to be contacted should they feel the need *'I know the support is there if I want it' (P5)*. Many felt that they had developed good relationships with their diabetes nurse over time and this was experienced as comforting and supportive *'My diabetes nurse is my rock' (P3)*. This was particularly evident when people felt that they had taken time to try and understand them as an individual *'I felt like she was really looking to understand, me, and how she could help me manage the diabetes better' (P4)*. Acknowledgement from the diabetes team that living with T1D was difficult and hard work was also experienced as being particularly valuable *'They were very kind of, we know. We know that people didn't look after and don't look after themselves at points in their life, we know that it's hard work' (P6)*.

Difficulties with diabetes team

However not all encounters with the diabetes team over time had been experienced as positive by participants. Some described not feeling supported or held in mind by the team *'There's not a lot of support there I guess (...) I'm sure they do lots of stuff but I just don't, I'm not in contact so I don't know it, or know them at all.'* (P1). Others described feeling 'told off' or blamed for high blood glucose even when they felt they had been working hard, which was upsetting *'Every time I went to the hospital for check-ups I got told off for the high blood sugars'* (P5). Difficulties managing the health system, such as in regard to appointments was also a common experience *'They either get cancelled or, you're waiting for hours'* (P5). One person spoke about experiencing significant distress when she was referred for what she felt was an inappropriate course of psychotherapy after being admitted to hospital with DKA *'Hospitalisation with DKA. (...) that was quite a difficult time. Just the whole, getting my head around that, and you know afterwards (...) they just said, we think it would be beneficial for you to go to this shrink, here's an appointment. (...) I went to shrink and (...) I was in floods of tears, for like 20 minutes, and he didn't mention my diabetes once (...) So I stopped going, because I was like I'm not going to talk to you about unrelated matters which to me don't mean anything when actually, you don't have a clue about diabetes, which is why I'm here in the first place.'* (P3).

Attending carbohydrate counting courses

Being referred to a carbohydrate counting course was described as a unanimously positive experience by all participants. *'And then I did the (...) course, which was great. That was, to be honest, I think that was the best thing I've ever done, positively, for turning the diabetes around.'* (P4). This appeared to be due to the increase in perceived control that

new skills and knowledge provided alongside a noticeable impact on quality of life *'And then I learn to carb count. So it could be, anything with carbohydrate that I eat, I know to have insulin with it. So I can eat, anything I want. As long as I counteract it with insulin.'* (P7).

Another benefit of attending was the opportunity to meet and share experiences with peers who truly understood diabetes *'One of the biggest things (...) after doing the (...) course was that there is actually other people out there who go through the same crap. Um, who deal with the same thing day in day out. Um, who, have been through the same thing you've been through'* (P6).

Simplistic view of diabetes

Many participants felt that diabetes and its management was viewed as overly simple by members of the diabetes team, which often led to feelings of frustration and a perceived lack of empathy *'So, it's almost like the teams have always felt that, diabetes is black and white. But it's not. And like, obviously you get the text books about diabetes. And they seem to follow that. And they don't seem to look at you as an individual as to why you might, be up and down'* (P7). This feeling often resulted from a perceived over emphasis on HbA_{1c} values, which many felt didn't fully encapsulate their experiences of managing diabetes day to day *'Most of the time I'm, between 12 and 17 and if my HbA_{1c} is still coming back good that's not, there's something not matching up there and that is what they look at,'* (P1). Some people also described feeling that recognition and support regarding the emotional impact of living with T1D was not considered important compared to managing blood glucose *'I feel like, I've never had any, real help with (...) the health system around diabetes at least for um, the emotional side of this disease. Which I think is like, you know, equal to getting the blood sugars sorted out, it's just as important.'* (P4).

Ways of coping

The final master theme encapsulates peoples reported ways of coping with T1D.

Discussing diabetes

Many people found it helpful to discuss T1D with others *'I do always like talking about it. Cos it's like a nice sort of, offload'* (P4) and in particular talking to other people living with diabetes and/or attending diabetes peer support groups *'I think actually talking to other diabetics is quite a good thing, because you always feel like you're on your own and nobody else quite understands but, there is a lot of people that do'* (P2). Others also found discussing T1D during psychological therapy as a helpful way of coping *'My own therapy has allowed me to learn coping mechanisms'* (P1).

Technology

Advances in technology were widely recognised as improving people's experiences of living with diabetes. This was due to additional opportunities to connect with others online *'Things like Facebook make that easier. Join groups. That helps.'* (P6), as well as improvements in medical technology helping to reduce the burden of treatment *'The new equipment, the technology has got so much better over the years'* (P2).

Not thinking about or engaging with diabetes

Some individuals talked about trying not to think about diabetes or not engaging with it too much as a helpful way to cope *'I guess a lot of my life I haven't really thought too much about the diabetes. I just tried to live [pause] as, I tried to live as everybody else has lived'* (P8). Some described trying not to place too much emphasis on diabetes so that they could feel 'normal'. However this also had downsides when needing additional support *'The main thing has been not making a big deal out of it, I think for me so that I still feel normal (...) the flipside of me trying to be normal is that sometimes, I could potentially be in a*

dangerous situation because people didn't realise the gravity of a hypo, or even know that I was diabetic' (P1).

Accepting and engaging with diabetes

Many people talked about how accepting diabetes was a pivotal step. When people stopped fighting against the fact that they were living with diabetes they experienced a reduction in its negative impact on their lives *'What's the point of ignoring the diabetes when it's there for the rest of my life? I might as well work with it, to kind of, get the most out of my life and, what I want.'* (P7). Others felt that deciding to take things day by day also helped to reduce pressure and worry about what might happen in the future *'You know, I might end up in a wheel chair. Or I might end up having a heart attack, pfff, don't know, don't think about it. Um, I just take each day as it comes really.'* (P8).

Hope and positivity

Some individuals described a sense of hope that things would be better in the future due to improvements and research *'A lot of things have changed over the years already there's still time to make a lot of improvements.'* (P2). Others described a sense of trying to search for positives wherever possible as being helpful *'I don't know if there is anything actually positive from being diabetic, but I think there's a lot of positives you can make, whilst being diabetic'* (P3). Adopting a proactive and positive attitude towards life with diabetes also helped when trying to live life to the full *'I haven't, let it, stop me from doing anything. I haven't gone I can't do that because I'm diabetic. I've gone oh, let me think about how I can do that with the diabetes'* (P7). Some people also described a sense of strength and positive growth as a result of their experiences, even if these were initially difficult *'I've been through a lot with the diabetes which I think has made me stronger as a person. I think*

I've learnt from it and I think I want to help others. I think that's a positive. And I think that I've coped with a lot.' (P5).

Discussion

A wide variety of experiences were reported by participants. The master themes that emerged from discussion were: experiences of diagnosis, physical impact of T1D, psychological impact of T1D, social impact of T1D, influence of healthcare teams and ways of coping. Some experiences were described as highly distressing whilst others were more easily managed. This was not fixed over time, and was often affected by individual differences and other life events separate to diabetes.

Implications for practice

The study findings are consistent with those of the DAWN studies (e.g. Nicolucci et al., 2013) that diabetes related psychological distress is a commonly experienced phenomenon. Distress could not be directly attributed to one specific cause but rather was related to how diabetes interfaced with a combination of different biological, psychological and social factors at any one time. Experiences of distress were regularly discussed, despite there being no direct questions about it in the interview schedule, suggesting that it is understood by participants as an intrinsic part of the experience of living with diabetes and not necessarily as an additional mental health issue. The findings also indicate that applying existing diagnostic criteria for depressive symptoms to experiences of diabetes related distress in practice may not fully capture the context of living with diabetes or be consistent with an individual's own view of these experiences. For example, being referred to generic mental health services lacking in diabetes specific skills and knowledge was experienced as extremely unhelpful and upsetting by one participant. These findings are consistent with

existing ideas surrounding diabetes related distress as accounting for the presence of depressive symptoms but being distinct from psychiatric illness (e.g. Fisher et al., 2014; Gonzalez et al., 2011). Awareness of this in practice is important in order to avoid the use of potentially inappropriate and unhelpful interventions for people experiencing significant diabetes related distress (Esbitt et al., 2013; Trigwell et al., 2008).

Response from healthcare staff appeared to play a significant role in people's experiences of living with diabetes. Whilst the majority felt that support with managing blood glucose from the diabetes team was extremely helpful, some participants felt that diabetes management was sometimes viewed as overly simple by staff teams. For example, focusing on HbA_{1c} results and glycaemic control without acknowledging people's individual differences and/or the psychosocial context within which this occurred. Focusing on glycaemic control to the detriment of other relevant psychosocial factors was experienced by many as a lack of perceived empathy from staff and minimised opportunities to consider how diabetes treatment interfaced with the rest of their lives, something which many felt was equally as important to discuss during appointments as control of blood glucose. Attempts from staff to understand diabetes management in the context of people's individual circumstances was highly valued by participants, and this is consistent with the findings of Kibbey et al., (2013) that satisfaction with diabetes care and acknowledgement as an individual can play an important role in reducing diabetes related distress. In addition to routine clinical outcomes such as HbA_{1c}, health related quality of life in diabetes is also considered an important outcome in its own right (Rubin & Peyrot, 1999). Therefore it is important to adopt a truly biopsychosocial approach to diabetes care in practice by considering the impact that any steps toward improving glycaemic control may have on an individual's psychosocial wellbeing and vice versa.

Many people described a sense of feeling alone and not being fully understood by others with regards to their experiences of living with diabetes. This is often exacerbated by stigma and lack of understanding from others, consistent with the findings of Schabert et al., (2013) that large numbers of people living with diabetes experience social stigma from others. Conversely, discussing experiences with other people living with the condition either online or in person was described as helpful and normalising, supporting previous findings of Due-Christensen et al., (2012) and Forlani et al., (2013) that feeling intuitively understood by peers is helpful. Consideration of this and facilitating the implementation and attendance of diabetes peer support groups may be a helpful step toward reducing distress in practice.

Acceptance of diabetes appeared to result in both improved psychological and physical wellbeing. Participants described this process as being driven by numerous factors such as: attending carbohydrate counting courses, developing complications, maturity and changing life priorities. It is important to remain aware of this process in practice and also how it was also not a one off task, appearing markedly different for each individual and with distinct challenges to overcome in order to helpfully integrate diabetes into their sense of self at different life stages. A frequently discussed time where people experienced difficulties with this was adolescence and early adulthood, supporting previous research findings that this can be a particularly distressing time for people living with T1D (Balfe et al., 2013; Scholes et al., 2013; Kibbey et al., 2013; Zoffmann et al., 2014). After accepting diabetes, individuals described a sense of strength and positive growth, consistent with reported experiences of post traumatic growth by those experiencing other serious medical conditions (Barskova & Oesterreich, 2009). Supporting people to fit diabetes management into their lives in a way that is least restrictive and distressing in the context of their life

stage, unique personal challenges and psychosocial circumstances may help to facilitate the process of accepting diabetes and improve health and wellbeing.

Limitations and implications for future research

The present study has a number of limitations. The sampling method utilised may have created a self-selection bias, with more enthusiastic individuals and/or those more comfortable discussing living with diabetes more likely to elect to participate in the study than others. This may have resulted in the study sample not being fully representative of all adults living with T1D, potentially reducing the generalisability of the findings. In addition, nothing is known about the distress or mental health histories of the study sample. This could have been an important factor in influencing people's decisions to participate and is something that could be considered further in future mixed methods studies.

Whilst the present study had a significant higher mean age (32) than previous qualitative studies of T1D involving children and young adults (e.g. Balfe et al., 2013; Scholes et al., 2013), the study did not recruit anyone older than 50. This means that the experiences of older adults living with T1D were potentially not represented in the collected data. The entirety of the sample were also White-British individuals, which may mean that the results are not fully generalisable to those with different ethnic backgrounds. Further research exploring the experiences of individuals who are older and/or from minority ethnic backgrounds living with T1D would help to expand knowledge concerning any specific challenges that these groups may face that have not been covered in the present study.

Some of the sample had also gone on to develop complications whilst others had not. This appeared to be a significant influence people's experiences of living with T1D. Complications were not explicitly focused on in depth during the present study and further

consideration of the experiences of a sample of people who have developed additional diabetes related complications could potentially further knowledge in this area.

Many people reported experiencing a lack of empathy from healthcare staff. This raises the question of why this may be occurring in practice. Are professionals not demonstrating this effectively or are people living with diabetes not hearing or receiving well intended approaches from staff? The DAWN2 study found that many healthcare professionals reported feeling unable to provide adequate support for psychosocial issues (Holt et al., 2013), and professionals in the UK have previously reported feeling de-skilled in dealing with psychosocial elements of diabetes management (Trigwell et al., 2008). This may be underpinning a reluctance to discuss psychosocial issues with patients due to fears about how to manage this in practice, which is sometimes experienced as staff not fully attending to their individual needs. Further research investigating the experiences of diabetes healthcare professionals when supporting people living with diabetes may help to answer these questions.

Conclusion

Adults living with type 1 diabetes report a wide variety of experiences related to the biological psychological and social components of the illness. Some of these are experienced as highly distressing whilst others are more easily managed. This is often dependent on individual differences and is not necessarily static over time. Further awareness of this in practice and a focus on diabetes and its treatment within the context of people's unique psychosocial circumstances is highly important in supporting people to reduce diabetes related distress, which can improve glycaemic control, health related quality of life and wellbeing.

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Section C: Appendices and supporting material

A thesis submitted in partial fulfilment of the requirements of
Canterbury Christ Church University for the degree of
Doctor of Clinical Psychology

APRIL 2015

SALOMONS
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Appendix A: Psychometric properties of self-report instruments used to measure diabetes related distress by studies included in the review

Of the 15 studies reviewed, 11 utilised the Problems Area in Diabetes (PAID) questionnaire (Polonsky et al., 1995) to measure diabetes related psychological distress. The PAID is a 20 item self-report tool designed to measure whether or not feelings related to diabetes and/or the process of diabetes management are perceived as a problem for the individual concerned. The PAID uses a 5-point Likert scale and generates a score of between 0-100 (higher scores indicate greater levels of distress), with an accepted cut-off point of 40 to indicate clinically significant diabetes related distress.

The PAID is considered overall to have good psychometric properties (Welch, Weinger, Anderson, & Polonsky, 2003). The PAID has demonstrated consistently high internal reliability, good item-to-total correlations, robust two-month test-retest reliability, and also correlates strongly with expected associated constructs, including: depression, emotional distress, fear of hypoglycaemia, disordered eating, HbA_{1c}, self-care behaviours, and the presence of diabetes related complications (Polonsky et al., 1995; Weinger & Jacobson, 2001). Furthermore, the PAID has shown high levels of cross-cultural validity in translated versions (e.g. Snoek, Pouwer, Welch, & Polonsky, 2000).

There is a strong overlap between constructs measured by the PAID and also measures used to screen for major depressive disorder (MDD; Fisher, Gonzalez & Polonsky, 2014). However, the fact that diabetes (or other health conditions) could be a contextual factor in experiences of depression are disregarded in measures typically used to measure MDD. This often results in scores of “sub-clinical” depression that still have a significant impact on the health and well-being of the person living with diabetes (Esbitt, Tanenbaum, & Gonzalez, 2013). The PAID has been demonstrated to more accurately indicate the presence of sub-clinical depression, clinical depression and diabetes related distress when compared with other measures of depression alone, including: Self-report measures for depression, structured clinical interviews and non-structured clinical interviews including psychiatric history when used with people living with diabetes (Hermanns, Kulzer, Krichbaum, Kubiak, & Haak, 2006). However, living with diabetes and experiencing depression are not mutually exclusive: Higher scores on some questions in the PAID related to feeling burnt out from managing diabetes and feeling depressed about living with diabetes were more strongly related to measures of clinical depression, suggesting a clinical need to also consider screening for MDD alongside diabetes related distress in some cases. Despite reported good psychometric properties and sensitivity, the PAID has received criticism for being overly long and for not sufficiently capturing levels of distress related to an individual’s healthcare providers (Polonsky et al., 2005).

One study also utilised the Diabetes Distress Scale (DDS; Polonsky et al. 2005) alongside the PAID as two measures of diabetes related distress. The DDS was developed by Polonsky et al., (2005) in response to criticisms of the PAID, and consists of 17 items which are subdivided across 4 subscales. These are Emotional Burden (EB), diabetes-related Interpersonal Distress (ID), Physician-related Distress (PD), and Regimen-related Distress (RD). The DDS is a 17-item test and utilises a 6 point Likert scale to generate an overall distress score and 4 subscale scores. A mean score of two or higher on any domain indicates moderate distress and three or higher denotes the presence of serious distress. The DDS

has also been demonstrated to have good psychometric properties. Fisher, Hessler, Polonsky, and Mullan (2012) found increases in diabetes distress as measured by the DDS to be associated with other expected constructs such as: higher HbA_{1c} levels, lower self-efficacy, less physical activity, and poorer diet. The DDS has been shown to have a generalisable factor structure as well as acceptable validity and internal reliability across the four subscales (Polonsky et al., 2005). Whilst both the PAID and the DDS have been shown to have acceptable psychometric properties, Graue et al., (2012) found the DDS to be preferable to the PAID for clinical and research purposes due to the ability to identify different sub-domains of distress. Even with the DDS being potentially more sensitive to diabetes related distress than PAID, it still recommended that the assessor review responses with individuals (regardless of their score) in keeping with comprehensive assessment of diabetes related distress and/or depression (Polonsky et al., 2005).

The Well-being Enquiry for Diabetics (WED; Mannucci, Ricca, Bardini, & Rotella, 1996), is a 50 item Italian-language self-report instrument of diabetes related QoL, with good reported reliability and sensitivity (Forlani et al., 2014). One of its four subscales (the Discomfort scale) aims to measure diabetes related worries and emotional status, and was used by one of the studies included in the review to measure diabetes related psychological distress. There is a dearth of studies about the psychometric properties of this measure that are written in English which makes a detailed examination of its robustness difficult.

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Appendix B: Participant recruitment poster

NHS Trust



Do you have type 1 diabetes (controlled by insulin)?

Have you had diabetes for 1 year or more?

Would you like the chance to win £50 worth of vouchers to spend at Amazon.co.uk?

My name is Michael Wilding, I am conducting a research project as part of my Doctorate in Clinical Psychology at Canterbury Christ Church University. I am interested in interviewing a sample of people about their experiences of living with type 1 diabetes.

If you might be interested in taking part or would like more information, please speak to a member of the diabetes team who can provide you with an information pack. Alternatively you can contact me directly at [REDACTED] or give me a call on [REDACTED]. I will be happy to tell you more about the research and answer any questions you may have. I look forward to hearing from you.

Appendix C: Participant information sheet**PARTICIPANT INFORMATION SHEET****Exploring the experiences of people living with type 1 diabetes**

Hello. My name is Mike Wilding and I am a Trainee Clinical Psychologist at Canterbury Christ Church University. I would like to invite you to take part in a research study. Before you decide whether or not you would like to take part it is important that you understand why the research is being done and what it would involve for you. Please talk to others about the study if you wish.

Part 1 tells you more information about the purpose of the study and what will happen to you if you take part.

Part 2 give you more detailed information about the conduct of the study.

PART 1**What is the purpose of the study?**

I am interested in talking to people living with type 1 diabetes. I would like to hear from people about their experiences of living with diabetes, and to think with them about how it may influence their health and well-being. It is hoped that the information gained from interviewing people will provide useful knowledge for professionals working with people living with diabetes, including those who might offer emotional and/or psychological support.

Why have I been invited?

A selection of adults living with type 1 diabetes have been invited to take part in the study. It is hoped that up to 15 people living with diabetes will take part.

Do I have to take part?

No, taking part in the study is entirely voluntary. Whether or not you decide to take part will not affect your care at the diabetes clinic in any way. None of the staff team will know whether or not you have taken part in the research.

What will happen to me if I take part?

If you would like take part, you will be invited to attend an interview. You will be asked to confirm that you have a copy of this information sheet and have read and understood it. You will then be asked to sign a consent form before beginning the interview with the researcher. You are free to withdraw at any time during the interview, without giving a reason.

You will be contacted by the researcher to arrange a time to meet for an interview. This can be either at your diabetes department, or the researcher can travel to conduct the interview at your home should you prefer.

On the day of the interview:

- first you will be asked to confirm that you have a copy of this information sheet and have read and understood it,
- You will then be given consent form to sign.
- You will then be asked to complete some details about yourself.
- After this the interview will begin, there will be a discussion about certain points related to some of the topics highlighted above, the interview will be audio recorded.
- Afterwards there will then be an opportunity to discuss the interview and ask any more questions.

The interviews are planned to last approximately one hour, but may be shorter or longer depending on how quickly the interview is completed. Your involvement should last no more than 2 hours.

Expenses and payments

- You will be given the option to enter an online draw to win £50 of Amazon vouchers as a thank you for your time. You can leave your email address on the consent form should you wish to do this. Please note that this will not be stored with the answers you give to the questionnaire in order to preserve anonymity.
- You will also be reimbursed (up to a maximum of £10) for travel expenses if the interview is conducted at the diabetes centre.

What are the possible disadvantages and risks of taking part?

It may be that some of the things discussed in the interview will be difficult and/or distressing for people to talk about, every effort will be taken to discuss things in a sensitive manner, however there is still a small risk that some of the things discussed might be upsetting. The researcher will be on hand to discuss any issues, you also have the option to take a break whenever you like, or to withdraw from the study at any time, without giving a reason.

What are the possible benefits of taking part?

No direct benefits are planned, although some people may benefit directly from the chance to talk and think about some of their experiences of living with diabetes with someone.

It is hoped that people may benefit indirectly, as the information gained from participants in this research may influence how diabetes services are developed in the future and that they take into account what people living with diabetes have talked about.

This completes part 1.

If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

PART 2

What will happen to the results of the research study?

The study will aim for publication in a peer review journal and may lead to further research in the future. Any identifiable information will be removed so that participants cannot be identified in any report/publication. Anonymised quotes from interviews may be included in published reports.

Will my taking part in the study be kept confidential?

Yes. Your information will not be shared with anybody outside of the research team consisting of

myself and two research supervisors. The only exception to this would be in the unlikely event that something was discussed which led the researcher to believe that there was a significant risk posed to either yourself or others.

The recordings of the interviews will be transcribed by the researcher, only the researcher and his two supervisors will have access to the original recordings.

The data collected will form part of the present study. Data will be stored in anonymous form on encrypted CD which will be kept in a locked cabinet at Canterbury Christ Church University. The data will be kept for 10 years following the completion of the project, as is university policy. After this time the data will be destroyed.

Who is organising and funding the research?

The research is being funded by Canterbury Christ Church University.

Who has reviewed the study?

The research has been reviewed by an independent research panel at Canterbury Christ Church University. The study has also been reviewed by a local NHS ethics review panel on 11/07/2014 and was given a favourable opinion on both occasions.

What will happen if I don't want to carry on with the study?

During the interview let the researcher know, and the interview will be stopped. You do not need to give a reason why.

What if there is a problem?

If you have any concerns with any aspect of the study, then in the first instance, please speak to me. I can be contacted on [REDACTED] or on [REDACTED]

If you remain unsatisfied with my response and wish to complain formally, you can do this through [REDACTED] Salomons Centre for Applied Psychology at Canterbury Christ Church University.

If participating in the study results in you experiencing personal distress, please contact your GP or contact NHS 111 by dialling 111 from any phone. The researcher will also be available directly after the interview to discuss any concerns and options for additional support from the [REDACTED] service should you feel the need.

Further information and contact details:

If you are interested in participating in the research, or you have any questions you would like to discuss with me, please either e-mail me at [REDACTED] or give me a call/leave a message on [REDACTED]. Please state your name and leave a contact number or e-mail address so that I can get back to you.

Appendix D: Letter of favourable opinion from NRES ethics board

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Appendix E: Letter(s) of R&D approval

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Appendix F: Participant consent form**CONSENT FORM – RESEARCHER COPY****Exploring the experiences of people living with type 1 diabetes**

Researcher:

Michael Wilding

Trainee Clinical Psychologist

Canterbury Christ Church University

Salomons Centre for Applied Psychology

Broomhill Road

Tunbridge Wells

TN3 0TF

Please initial boxes below:

1. I confirm that I have read and understood the information sheet, and have had an opportunity to ask questions.	
2. I understand that my participation is voluntary and I am free to withdraw at any time, without giving a reason.	
3. I agree to take part in the above study	
4. I agree to the interview being recorded.	
5. I agree to the use of anonymised quotes in publications.	

Name of Participant _____ Date _____

Signature _____

Name of Researcher _____ Date _____

Signature _____

PLEASE TURN OVER & COMPLETE THE SECOND COPY OF THE CONSENT FORM

CONSENT FORM – PARTICIPANT COPY**Exploring the experiences of people living with type 1 diabetes**

Researcher:

Michael Wilding

Trainee Clinical Psychologist

Canterbury Christ Church University

Salomons Centre for Applied Psychology

Broomhill Road

Tunbridge Wells

TN3 0TF

Please initial boxes below:

1. I confirm that I have read and understood the information sheet, and have had an opportunity to ask questions.	
2. I understand that my participation is voluntary and I am free to withdraw at any time, without giving a reason.	
3. I agree to take part in the above study	
4. I agree to the interview being recorded.	
5. I agree to the use of anonymised quotes in publications.	

Name of Participant_____ Date_____

Signature_____

Name of Researcher_____ Date_____

Signature_____

REQUEST FORM

Please tick the appropriate box below:

	YES	NO
I would like to be entered into a prize draw to win £50 of Amazon vouchers		
I would like to be e-mailed a summary of the research findings		

If you have answered “YES” to either question, please provide your e-mail address below so you can be notified of a win or the study findings (your e-mail address will be stored separately from your study data in order to preserve anonymity):

--

Appendix G: Semi-structured interview schedule

INTERVIEW SCHEDULE

- Explain procedure.
- Check information sheet has been read and understood and consent form signed.
- Ask the participant if they have any further questions before starting.

- 1) I wondered if you could start by telling me about when you were first diagnosed with diabetes?**

Prompts: **How long ago was this?**

***How old were you at the time?**

Can you recall what that meant to you at the time?

- 2) Has the way you have felt about living with diabetes changed over time?**

Prompts: **In what ways?**

***could you say more about X experience and how it affected this view?**

***why do you think that was the case?**

What sort of things have made it easier to live with?

What sort of things make it harder?

- 3) Can you describe how diabetes effects your relationships with other people?**

Prompts: **e.g. partner/ family members/ friends/ colleagues?**

- 4) What role does the diabetes team have in your life at the moment?**

Prompts: **What sort of things do the diabetes team do that is helpful?**

What in your opinion would be a positive change to the care you receive?

- 5) How do you think life might be different if you didn't have diabetes?**

Prompts: **Could you describe some difficult times you have experienced in relation to living with diabetes?**

Can you tell me about some of the more positive aspects about living with diabetes?

Has living with diabetes changed the way you think and feel about yourself?

- 6) *Looking to the future, what comes to mind when you think about living with diabetes?**
- 7) * What has it been like to talk about living with diabetes in the way you have done with me today?**
- 8) Is there anything else that you think I should have asked or that you would like to tell me?**

General Prompt Questions:

What do you mean by that?

Can you tell me a bit more about that?

And how did you feel?

Why was that?

Tell me what you were thinking?

DEBRIEF:

- **That was all of the questions.**
- **Did you want to ask anything about what we have discussed?**
- **How are you feeling?**
- **Do you feel I need to talk to anyone about how you are feeling?**
- **Provide details of self-referral to [REDACTED] if necessary.**

* Questions marked with an asterisk were added to the interview schedule as the study progressed in response to discussions with previous participants

Appendix H: Summary report for participants

Salomons Centre for Applied Psychology
Canterbury Christ Church University, Runcie Court
Broomhill Road, Tunbridge Wells
TN3 0TF

20th April 2015

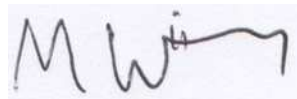
Dear X,

Firstly I would like to take this opportunity to say thank you once again for taking the time to participate in this research study. I interviewed 8 people living with type 1 diabetes and the study has now been completed.

I am contacting you as you indicated that you would like to receive a short summary of the study results. This can be found in the attached short summary report. If you would like any further information or to receive a copy of the study once it is published, please contact me before the end of September 2015 by e-mail or telephone on:

[Redacted contact information]

Kind Regards,

A handwritten signature in black ink, appearing to read "Mike Wilding".

Mike Wilding

Clinical Psychologist in Training

Salomons Centre for Applied Psychology
Canterbury Christ Church University

Summary of findings: Exploring the experiences of people living with type 1 diabetes

Background

Understanding people's experiences of living with diabetes is important because it can help health professionals provide the best care and support possible. Research into people's experiences of living with diabetes has been ongoing for many years but has often not investigated people's lived experiences in rich detail. Previous research that has done this has tended to focus on adults living with type 2 diabetes and/or children and young people living with type 1 diabetes, meaning that adults living with type 1 diabetes are currently an under researched group of people. Because of this gap in knowledge, this study aimed to find out more about the experiences of a sample of adults living with type 1 diabetes.

Study overview

I interviewed 8 adults with type 1 diabetes and explored their experiences of living with the condition. Interviews were transcribed and analysed using a process called interpretative phenomenological analysis (IPA) in order to group these experiences into themes.

Study findings

Six key themes were identified from your combined experiences, these were:

Experiences of diagnosis

Many of you described feeling unwell and then being diagnosed as a scary and stressful time for both yourselves and your families, often resulting in a lot of changes to your lives. However some of you that were not old enough to remember being diagnosed felt that this meant that it was easier for you to come to terms with things, as you had not known any differently. Some of you also talked about feeling that you left hospital after being diagnosed without a great deal of information about how to manage diabetes well.

Physical impact of diabetes

Almost all of you talked about feeling frustrated and confused when trying to manage your diabetes day-to-day, especially when it not clear why your blood sugars appear to go up and down or 'yo-yo'. However, you also talked about a sense of pride and achievement when you are able to manage your diabetes well for periods of time. Many talked about how trying to fit diabetes management into your lives required a great deal of planning and effort, and sometimes this could make it more difficult to do things you would like to do. Some of you also talked about developing additional diabetes related complications. This often left people feeling scared and out of control, for some this also led to a change of focus with regards to diabetes.

Psychological impact of diabetes

Many of you described feeling distressed about living with diabetes at one time or another. Feeling upset or worried is not fixed and often changes in response to other things that are happening in your lives. Some of you felt that changes to your blood sugar levels affected your mood, whilst other people felt ground down by a sense of constantly being aware of

how you felt, what you were eating and/or worrying about your blood sugars. Many of you talked about how diabetes influenced your development and sense of identity, especially during adolescence where lots of you described a period of 'rebellion' against diabetes. However, many of you felt becoming more mature as you grew older helped you to prioritise diabetes more highly and try to improve your control.

Social impact of diabetes

A lot of you worried that diabetes had a knock-on effect on other people around you, such as partners, family, friends and colleagues. Some of you described sometimes being grumpy with those close to them if their blood sugars were high or low. Many of you felt guilty about this, but also felt it was important to emphasise that often you did not feel 100% in control of your behaviour when this happened. Some felt that needing to plan ahead also made it difficult to be as 'spontaneous' as others which often impacted on social events. Many of you talked about experiencing stigma and a lack of understanding from others. Such as being asked to do injections in toilets and first aids rooms, people confusing type 1 and type 2 diabetes, and experiences of people not really understanding some of the difficulties you face because you looked 'fine' and 'normal' on the outside. Despite some of these difficulties, most of you talked about receiving help and support from those around you as comforting and helpful.

Influence of healthcare teams

Diabetes teams appeared to be an important factor in how many of you experienced living with diabetes. Most of you described the team as helpful in supporting you to manage your blood glucose, and some of you described regular visits with the diabetes nurse as particularly helpful, particularly if you had a chance to build a strong relationship over time. Despite this many of you felt that sometimes the team placed too much emphasis on blood sugars and HbA_{1c} results, often taking a 'textbook' approach to managing diabetes over acknowledging you as individuals and thinking about how diabetes management fitted into the rest of your lives. Many of you also talked about feeling as if there was a lack of emotional support from the diabetes team. Almost all of you felt that being referred to carb counting courses by the diabetes team, such as DAFNE and SADIE, were very helpful experiences. People described a feeling of increased control over their diabetes, and many of you also valued the chance to meet others living with diabetes and share and learn from each other's experiences.

Ways of coping

You described a number of different way of coping with diabetes. Some people described not thinking about it and trying to feel as 'normal' as possible as a helpful way to cope. Others talked about 'accepting' diabetes as part of you and trying to work with it rather than against it in order to get the most out of your lives. Others talked about using new technology such as insulin pumps, as helpful. Many of you felt discuss diabetes with other people living with the condition was helpful, such as online discussion boards or attending peer support groups. Many of you also talked about trying to maintain a sense of hope and positivity for the future. Many of you talked about how much things have improved in the

time since your diagnosis and that there is no reason why this should not continue. Some of you also talked about experiencing a sense of strength and positive growth as a result of some of your experiences.

Summary and conclusions

All of you reported a wide variety of experiences related to living with type 1 diabetes. Some of these were experienced as distressing and upsetting whilst others were more easily managed. This was not fixed over time, and was often affected by differences in you as individuals and other things that were happening in your lives outside of diabetes. I am recommending further awareness of this by diabetes healthcare staff and a focus on diabetes and its treatment within the context of people's unique circumstances as highly important in supporting people to reduce diabetes related distress.

Appendix I: Example of coded Interview transcript for participant 4 (27 y/o male living with T1D for 12 years). All names are pseudonyms.

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Appendix J: Overview of theme development

Master Theme	Sub Theme	Emergent Theme(s) Related to Sub Theme
Experiences of diagnosis	Process of diagnosis	Feeling unwell Hospital admission Receiving diagnosis Lack of information
	Reacting to diagnosis	Disbelief and denial Not knowing any different Scared and upset Relief
	Adjustments and changes	Changes were sudden Difficult for parents to accept Hard for siblings There wasn't much change Things just happened – Just got on with it
Physical impact of T1D	Experiences of high blood glucose	Feeling awful Diabetes is confusing and hard to predict Running blood sugars high as a way of coping
	Experiences of managing blood glucose	Feeling out of control – Up and down blood glucose Finding logic and a pattern is hard work

		Lack of knowledge Gaining skills Sense of pride and achievement
	Experiences of hypoglaecemia	Feeling ill when hypo Hypoglaecemia is frightening Hypos affect day to day life
	Feeling frustrated and restricted by treatment regimes	Day to day life restricted by treatment Diet and eating influenced by insulin Extra planning and effort Extra awareness of body and diet Limits of technology Negative impact on body and body image
	Additional health complications	Developing complications is scary Complications lead to change of focus Complications restrict life further Experiences of DKA
Psychological impact of T1D	Psychological and emotional distress	Depression, distress and sadness Fear and anxiety Frustrating and annoying Emotional impact is important but hard to talk about Negative impact is not fixed
	Constant awareness and worry	Diabetes is there 24/7 – No time off Worrying about blood glucose levels

Social impact of T1D		<p>Worrying about developing complications</p> <p>Worries about children</p> <p>Constant awareness of T1D – Difficult to be present</p> <p>Feeling like a failure – Getting it wrong</p>
	Behavioural impact of T1D	<p>Physical symptoms affect mood and behaviour</p> <p>Awareness of impact of behaviour on T1D</p> <p>Difficult to be spontaneous</p>
	Impact on development and sense of self	<p>Impact on self-development</p> <p>Feeling different – Why me?</p> <p>Rebelling</p> <p>Maturity and changing priorities</p> <p>Diabetes is a part of me</p>
	Perceived impact on others	<p>Feeling a burden to others</p> <p>Impact on family members</p> <p>Impact on partners</p> <p>Impact on work</p> <p>Feeling guilty about the impact on others</p>
	Help and support from others	<p>Support from partners, family members and friends</p> <p>Support from work colleagues</p> <p>General public have more knowledge</p> <p>Awareness from others and sharing experiences is normalising</p>

		Balancing independence and need for support
	Stigma and lack of understanding from others	<p>Feeling alone – people don't understand</p> <p>Difficult for others to understand hypos</p> <p>Experiences of social stigma</p> <p>Confusion between T1D and T2D</p> <p>Looking fine and normal but not feeling fine</p>
Influence of healthcare teams	Support from diabetes team	<p>Support with managing blood glucose</p> <p>Regular support from the diabetes nurse</p> <p>Reassurance of additional health checks</p> <p>Helping you think</p> <p>Support with insulin pumps and other technology</p> <p>Recognition of hard work</p> <p>Acknowledgement and treatment as an individual is important</p> <p>Help is there if I need it</p>
	Difficulties with diabetes team	<p>Diabetes team not very involved</p> <p>Feeling told off or blamed by the diabetes team</p> <p>Poor communication</p> <p>Inappropriate referrals to mental health services</p> <p>Difficulties navigating the health system</p>

Ways of coping	Attending carbohydrate counting courses	Gaining new knowledge Attending course improved quality of life Attending the course helped improved control of blood glucose Meeting and learning with other people living with T1D
	Simplistic view of diabetes	Lack of acknowledgement and treatment as an individual Too much emphasis on HbA _{1c} Lack of recognition and support for emotional and psychological difficulties Simplistic view of diabetes management
	Discussing diabetes	Attending Diabetes support groups Discussing diabetes is helpful Psychological therapy has helped Sharing experiences – I'm not alone
	Technology	Access to information Improvements in technology
	Not thinking about or engaging with diabetes	Not thinking about diabetes – Just get on with it Not engaging with diabetes care Trying to feel normal – Not making a big deal out of it

Accepting and engaging with diabetes	Accepting and engaging with diabetes Taking it day by day Working with it rather than against it
Hope and positivity	Hope for the future Small rewards Staying positive Strength and growth Trying not to be held back by diabetes

Appendix K: Overview of Ahern's (1999) criteria for good quality reflexive bracketing

1. Identify interests that as a researcher, you might take for granted in undertaking this research.
2. Clarify your personal value systems and acknowledge areas in which you know you are subjective.
3. Describe possible areas of potential role conflict.
4. Identify gatekeepers' interests and consider the extent to which they are disposed favourably toward the project.
5. Recognise feelings that could indicate a lack of neutrality. These include avoiding situations in which you might experience negative feelings, seeking out situations in which you will experience positive feelings (such as friendly and articulate respondents), feeling guilty about some of your feelings, blaming others for your feelings, and feeling disengaged or aloof.
6. Is anything new or surprising in your data collection or analysis? If not, is this cause for concern. Consult colleagues before you assume that you have reached saturation in your data analysis. You might be bored, blocked, or desensitized.
7. When blocks occur in the research process, reframe them. Instead of getting frustrated when things do not go as planned, ask yourself, "Are there any methodical problems that can be transformed into opportunities?"
8. Even when you have completed your analysis, reflect on how you write up your account. Are you quoting more from one respondent than another? If you are, ask yourself why. Do you agree with one person's sentiment or turn of phrase more than those of another? If so, go back to your analysis and check that an articulate respondent has not biased your analysis by virtue of making your analytic task easier. Did you choose to write up the account in the first or third person? Why?
9. Consider whether the supporting evidence in the literature really is supporting your analysis or if it is just expressing the same cultural background as yourself.
10. A significant aspect of resolving bias is the acknowledgment of its outcomes. It is also worth remembering that even if preconceptions and biases are acknowledged, they are not always easily abandoned. An indication of resistance to abandoning bias includes consistently overlooking data concerning a different analytical conclusion than the one you have drawn. Discussion with a co-coder should counteract this analytic blindness.

Criteria extracted from Ahern (1999, pp. 401-410)

Appendix L: Transcript of bracketing interview

This has been removed from the electronic copy

Appendix M: Abridged research diary

The following has been extracted from a reflective journal regarding the research process.

2012	
November	Potential MRPs presented today at research fair. Currently interested in project looking at people with a learning disability who have diabetes. There is still possibility to create MRP not on the list based on own ideas, not ruled out as option just yet.
October	Met with one potential supervisor for LD and diabetes project. Also in discussion with another potential supervisor regarding another idea concerning psychological support for diabetes in the general population.
December	Supervisor selection form is due in soon. Need to decide on which idea to pursue, both potential supervisors are interested in working with me. Decided to go for my own idea conducting a survey based design investigating the psychological support for people living with diabetes and how people living with diabetes would potentially like this delivered in practice (if at all). Have identified internal supervisor with space. Now need to find external supervisor willing to supervise.
2013	
January	E-mailed some potential supervisors in the area who may be willing to supervise project idea. Meeting with 2 potential supervisors soon to discuss ideas. Identified external supervisor who is interested in project, appeared very interested in the area following meeting.
February	Supervisor selection form handed in.
March	Began preparation of research proposal. Interesting completing further literature search to expand on my previous knowledge.
May	Discussed draft research proposal with service user consultants with interest in research. They feel the research would have value and that people living with diabetes might benefit from further psychological support. Research proposal due soon, having difficulty finalising proposal and narrowing the research down into a specific enough question. Research proposal submitted.
June	Research proposal review panel today. Experienced process as difficult (suspect I took some of the feedback too personally). Panel have suggested that I have tried to take on too much, in an area that may be a little 'too close to home'. I am required to revise and re-submit proposal for August. I have been considering feedback from panel and discussed with supervisors following a bit of a breather. One comment is particularly standing out for me, that panel felt that I have made a number of assumptions which have formed the basis of my initial proposal, namely that psychological support for people living with diabetes would be helpful and that most people would want it. The panel suggest that it may be helpful to explore what people living with diabetes think about their experiences and to consider how psychological support may or may not fit within this as a more appropriate course of action.
July	Visit to Diabetes UK (charity) head office in London today. Discussed the beginnings of revised research proposal with head of research. He appeared interested in the project and suggested that linking in with research about to be published concerning diabetes related distress as part of the DAWN studies in their practitioner journal would increase its relevance and publishability.

	Discussed meeting with Diabetes UK with external supervisor, who suggested thinking about qualitative methodologies as well as possibly focusing on one type of diabetes (i.e. just type 1) in order to narrow down the research questions. I too feel these are good suggestions for the revised proposal. Now need to decide which methodology would be most applicable - possibly grounded theory or IPA. After research about different philosophical and theoretical positions decided on IPA for methodology due to the double hermeneutic allowing for me to draw upon my own personal experience of living with diabetes. Both supervisors also feel IPA is best fit for the research questions and that the explicit interpretative nature of this method will help to include my personal knowledge in the study in a way that adds extra depth to the research.
August	Revised proposal submitted.
September	Revised research proposal has been approved – feelings of significant relief and validation that research idea is now being viewed as valid and useful by multiple sources (e.g. Review panel, supervisors, and Diabetes UK). Minor changes to consider following second review - now onto NHS ethics approval.
October	Begin IRAS process – very long form! Lots to consider and identify on form.
November	Struggling to begin getting stuck in to IRAS process. Internal supervisor has just started two month sabbatical and very limited time to discuss research and provide support with this. Noticing feelings of particular anxiety that project will not be viewed as worthwhile by ethical review panel – possibly linked in with my experiences as a patient and/or resonating with first research review panel?
2014	
January	IRAS application moving slowly after Christmas break. Booked meeting with supervisors to discuss this.
February	Helpful meeting with external supervisor to focus process – very validating experience and helped to narrow down what value research will potentially bring once completed – this is something I had lost sight of in last few months. Beginning to get back on track.
March	Beginning to make contact with local diabetes teams in order to discuss project, potential recruitment and identify support and local collaborators – very nervous about taking this step, and I am surprised at some positivity of feedback and interest, even from busy consultants that I felt may have not been overly interested.
April	IRAS form is coming together – still lots add to form and may be tight for time with data collection after waiting for review panel date. May have to consider deferred submission.
June	NHS ethics application submitted – good news is research qualifies for a proportionate review. This means review will happen in 1 or 2 weeks instead of many months - should speed up process and regain some lost time.
July	Ethical review panel today, received a phone call from principal reviewer. Feedback was positive (again was surprised/particularly anxious about this) have received letter of conditional ethical approval - now a few minor conditions to change for favourable opinion.
August	Local R&D approval request submitted to one NHS trust that is willing to support the research. Conditions of full ethical approval have been met and acknowledgement received – now to continue with local R&D approval for the 2 trusts that are interested in the research. R&D approval for first trust received, now to begin recruitment whilst continuing with R&D approval for second trust.

	<p>Delays with receiving authorisation of local collaborator with second trust for R&D approval – frustrating.</p> <p>Undertook bracketing interview today with colleague. Many useful reflections and things to consider further:</p> <p>Interesting to consider some of my assumptions and motivations for completing this research. Given my lived experiences of type 1 diabetes and experiences accessing services in relation to this it is important to be aware of these.</p> <p>Some of the discussion revolved around where might my personal interest in diabetes related distress have come from. Ahern (1999) recommends clarifying ones personal value systems and areas where you are subjective. related to this, I recounted some of my personal experiences of occasionally feeling a lack of acknowledgement from others that diabetes is serious, and that my own distress about living with diabetes at times has not been validated. I wonder if I am also wanting to give others an opportunity for these experiences to be heard and acknowledged? I also became more aware of my own motivations to see more specialist psychological support for people living with diabetes in practice, as I currently feel this is often overlooked. I recognised this was an important driver behind my first unsuccessful project proposal and must be careful to hold this in mind throughout the remainder of the study progress.</p> <p>We also explored situations that so far have felt particularly anxiety provoking for me. This was discussed with the aim of identifying feelings that may indicate a lack of neutrality for me in parts of the research process, as recommended by Ahern (1999). I talked in particular about contacting diabetes teams and applying for ethics as periods of particular anxiety for me. At these moments I felt that I would have a fight on my hands to convince others of the value of my research. I have experienced surprise that in general people are interested in project, and that many of these are not people living with diabetes themselves. This feels strange given own experience of often feeling that the psychological impact of living with diabetes was not always acknowledged or thought about by others and/or diabetes teams. This may be fuelling anxiety around meetings with other professional's and receiving feedback about the project. I suspect this also might have been partially behind my roadblock with getting started with the IRAS form. It will be important for me to be aware of this when I conduct my interviews as a number of my questions involve discussions about how people experience their relationship with their diabetes team, and my own views about this have the potential to influence my questioning.</p>
September	<p>Still problems with second trust's R&D department – in continued dialogue with R&D department about this who are helping to push this forward on my behalf. Beginning to arrange interviews with some potential participants from trust number one.</p> <p>Now I have ethical approval – arranged meeting with both supervisors, to discuss ideas for section A - exciting meeting and injected enthusiasm. I will try to pull some of this thinking together and begin the section A write-up whilst also collecting data for section B concurrently.</p> <p>Additionally, following the recent bracketing interview I have been reflecting on areas of possible role conflict as per Ahern's (1999) criteria. A major consideration to emerge from the bracketing interview is whether or not I disclose my own diabetes prior to completing the interview or not. This is a potential conflict between my role as someone living with diabetes and also as a researcher. I discussed this with my supervisors and decided not to disclose this at the beginning because it may influence how people decide to describe components of their</p>

	<p>experience if they presume me to have prior knowledge or experience myself. Instead I shall disclose this at the end of the interview as part of the debrief. Finally managed to arrange a meeting with the diabetes team from the second trust with support of my external supervisor, team interested and keen to support the research, hopefully should speed up R&D approval process now. Beginning to meet first participants and conduct interviews.</p>
October	<p>First two interviews completed. Very interested to get started. Both respondents report quite different experiences and appear to be in different stages with life with diabetes, both in terms of age and how they view and respond to it – this appears to have different impacts for them on an individual level and how they view the diabetes team. It will be important to try to give equal credence to these differences in the report write up and not attend to one more than the other based on my own experiences. I was surprised to hear that one participant had described her relationship with the diabetes team as highly positive and supportive for the most part. Ahern (1999) recommends giving extra attention to areas of the data collection and analysis that is particularly surprising for you. I am thinking about my reaction to this, on some level I feel jealous that this individual is describing a positive relationship to the support network that I do not feel I have always had myself. Additionally I notice myself being drawn to discount this from my thinking and future questioning because it is not consistent with my experience. I must try to keep this in mind and to give it equal credence to more negative reports in the study write up.</p> <p>It is difficult to find time between completing interviews, transcribing, arranging others, working on section A, and noting initial themes. Meeting with internal supervisor soon to discuss initial theme development that may help to focus this. Useful meeting with supervisor to discuss initial reflections and theme development. Provided some useful additional insights and things to consider. On the whole they felt I was interrogating the data well.</p>
November	<p>R&D approval for second trust finally received after long delay. Beginning to recruit participants from this trust ASAP.</p>
December	<p>Three more interviews completed – interviews are now taking slightly longer, perhaps as I relax into the process and/or introduce lines of questioning informed by previous interviews. Also beginning to notice some convergence and divergence in people's stories. Experiences of distress are coming up regularly. This is despite me not explicitly asking people about psychological or emotional issues. Also this distress appears to be interwoven into the day to day experiences of living with the condition and not necessarily contingent on one or more specific events.</p>
2015	
January	<p>Two more interviews completed. Met with supervisor to discuss theme development. Discussed that although I have described people's experiences well and generally remained faithful to the data, I am maybe struggling to take the hermeneutic leap and add further interpretation to people's experiences. Upon reflection, this part of the analysis (i.e. taking a hermeneutic leap) feels like a 'block' in the research process described by Ahern (1999). I discussed this with my supervisor with a view to reframing this block in order to transform it into an opportunity as Ahern suggests. I talked about feeling a strong sense of responsibility to tell people's stories and to get it 'right'. My supervisor discussed the importance of trying not to feel constrained by this as long as I can feel confident in what I am doing and why – the aim is not to try to remove bias completely (that is impossible) but to try to acknowledge it and be aware of it</p>

	throughout theme development. Will re-visit themes and attempt to take more of an interpretative stance following the meeting.
February	<p>Final interview completed, adding transcripts to NVivo computer software which is extra work but is helping me to organise peoples words and organise theme development. Section A also progressing well, first draft should be ready for feedback soon.</p> <p>All transcripts have also been sent through to external supervisor who wishes to read them all in full, this will be helpful when evaluating my theme development later down the line.</p>
March	<p>Section A draft complete some positive feedback and minor changes to make but shouldn't take long to get into good shape.</p> <p>Analysis is now more or less finished and I can begin to write up section B results In line with Ahern's (1999) recommendations. I am taking some time to reflect on how I have chosen to write up the study findings. I am noticing that I am being drawn to include example quotes from 2-3 participants in particular. This is because they tended to speak in a succinct way and it is making my task of writing the study up easier. However on another scan through there are other example quotes from other participants that I can/would like to use, but I may need to cut words from other areas to include them. I will re-visit the results section to try to include quotes from all participants roughly equally where possible.</p>
April	<p>Draft of section B sent to supervisors – might be tight to get feedback incorporated before the deadline.</p> <p>I do not feel I will have things quite to the stage I would like in time for the initial hand in, I have discussed with supervisors and my manager the possibility of a 2 week extension.</p> <p>Extension agreed which should give me time to complete the work to the required standard.</p> <p>Summary report of results has been sent to participants. Have received some initial feedback – largely positive and participants feel that I have captured their experiences well. Many are excited to see something typed up and 'real' and that their experiences could possibly help others in the future.</p> <p>Writing ethics and R&D end of study report and tying up loose ends preparation for submission</p>

Appendix N: List of example interview quotations supporting each sub theme

Experiences of diagnosis

Process of diagnosis

'I was just drinking gallons of water, I was really thirsty, really tired' (P1)

'I was on holiday (...) and, I was drinking loads and going to the toilet loads and all the normal symptoms' (P2)

'I started wetting the bed, up to 3, 2 to 3 times a night. Um, excessive thirst. Um, extremely skinny. Complaining of achiness. Feeling ill permanently.' (P7)

'I was thirsty, uh, and I had lost, I was quite a chubby kid, um, and I'd lost, I'd lost weight,' (P8)

'My mum caught the symptoms within the first day, and I was straight in the doctors and on insulin within like 6 hours' (P3)

'Mum and Dad took me to the hospital nearby and, I got diagnosed' (P2)

'My mum told me (...) that they had a phone call from the hospital, you know, the middle of the night actually (...) saying, they didn't expect me to make it. They thought it was like pneumonia, something else, I can't remember. And there's only, at you know, a later stage they did, they did a test that they discovered, um, you know, diabetes and started giving me, giving me insulin.' (P8)

'You're in hospital, they, keep you on monitor, and keep you in there for like 3 days and, give you like, really, not very comprehensive instructions on how to manage the disease and then send you home. And, leave you to sort of get on with it I guess.' (P4)

'I wasn't really told, how to really manage it, we were just said ah you know, give a set dosage at breakfast, lunch and dinner, erm and that was about it really.' (P1)

Reacting to diagnosis

'I guess there was like, the classic sort of slight disbelief. I remember, early, early on, probably for the first like week or so. Basically just being like yeah, no, you know, it's fine, I'm not actually diabetic, you know, it doesn't mean anything.' (P4)

'When I was first diagnosed it was more of a relief to know something was wrong. And that it wasn't just people thinking I was just being attention seeking. [Laughs] I was like, 'I actually am ill.' (P7)

'It was a scary time.' (P5)

'I don't really remember too much about the, um, about the actual diagnosis myself. Because I was just too young really.' (P6)

'I haven't known any different which I think is probably easier' (P2)

Adjustment to changes

'So. I've started off on 2 injections, then rapidly went on to 4. So. Quite a lot to deal with at 9.' (P7)

'It would have been hard for my brothers and sisters in the house because, um [pause], I would, I was like suddenly this like ill child and they probably would have felt, (...) very like concerned about me' (P4)

'I think my oldest brother struggled quite a lot because (...) he always says like "Ohh, I was dragged to this hospital appointment, dragged to that hospital appointment"' (P3)

'When I was a child, my brother used to watch out for me all of the time' (P2)

'I mean it was, really hard for my mum and dad to have to, accept that I got the disease, as it was for me.' (P4)

'They hated the idea of having to give me injections, but they, said that, when I was first diagnosed they couldn't bear me sitting across the other side of the room while they watched a nurse giving me an injection. So they wanted to get involved, they wanted to do it' (P6)

'It was really really scary, scary times for my, uh for my parents actually' (P8)

'I had food allergies as a child so I was on a sugar free diet anyway (...) and because I'd been on a strict diet anyway, losing out on certain foods wasn't that big a deal to me.' (P7)

'At home, the diet was set around my brother anyway so, there wasn't that much change and I knew everything that was going on (...) yeah, it was quite good because I just knew it, I knew what it was and it wasn't a scary thing.' (P3)

'I guess I just, just like any, just like children I just sort of got on with it,' (P4)

'I kind of dealt with it quite quickly, and just got on with it.' (P7)

'Umm, and I think, being 11 it just kind of, it just happened' (P3)

Physical impact of T1D**Experiences of high blood glucose**

'I just feel awful, I have headaches a lot of the time anyway so they get worse' (P2)

'When I've got high glucose I do feel crap, headaches, and it, all the classic stuff and, I get kind of, grumpy,' (P4)

'The frustrations of why's my blood sugar high when I have done the right amount of insulin? (P5)

'It can get frustrating, (...) especially if you don't know why it's quite so high, it's, you know quite a few of them I can't explain.' (P2)

'Thinking about it I probably just run high most of the time (...) it's probably more the fact that I'll just run high just to stop that risk of being low, which yeah, isn't good, so, yeah (P1)

'I just, you know, it's the whole, um. If I run at 6 I hypo more frequently, if I run at 10 I don't feel any different and I don't hypo as frequently so why not run at 10?' (P6)

'I used to, and I still do to a certain extent run my blood sugars before bed, quite high. In the teens. That was a security measure for me.' (P5)

Experiences of managing blood glucose

'I've always gone up and down. Even when I eat the same thing, on the same day. My sugars go up and down.' (P7)

'I was always up and down, up and down all the time.' (P6)

'And then I was having like severe drops and highs' (P3)

'So there's just the fact that there was all of these other factors, that you can't really control for and you can't, you can't sort of pre-emptively manage, you know, you have to reactively manage them so, that's really frustrating I found.' (P1)

'I wasn't schooled in anything about, anything anywhere near like carbohydrate counting. There's no logic, it was all just like, hit and miss.' (P4)

'Generally I go on how I feel or how the sugars are day to day. Rather than see the pattern which isn't really very helpful, I should look and see the pattern more often.' (P2)

'And doing a few more blood sugars that, then, you start realising what's going on. And, actually, (...) it wasn't until I then starting twigging, I was like it's all about the data analysis really, it's what it comes down to, is knowing where to see those spikes and what the commonality is between all those spikes. And eliminating that. Or, making allowances for that. (...) It's two ends of the spectrum. One, in that it's a much, a much bigger pain in the arse. But, it gives you better long term results. Um, and short term results' (P6)

'You have to give it a lot of your time and thought. You have to write down sugars in a diary or look at them on your computer graphs or whatever.' (P4)

'And then I learn to carb count. So it could be, anything with carbohydrate that I eat, I know to have insulin with it. So I can eat, anything I want. As long as I counteract it with insulin.' (P7)

'So it doesn't matter if you have a big meal, bigger meal than normal you just inject the right amount of insulin for it and vice-versa really, but if you want some food, there's nothing to stop you to have that food, as long as you know, and you give it your best shot the amount of insulin' (P8)

'I've gone from like 9.7 down to 7.3 in the last 2 months is, yeah.

On the HbA_{1c}?

Yeah

And what's that like, to have brought the HbA_{1c} down?

I'm so proud of it [laughs] it's almost like, getting your degree results all over again just like ooooooh, you did good, you got a 1st type thing.' (P3)

'And, you know, stuff like that will give me like a, a sort of a, like a happiness kick because. Yeah, and mainly like, the, the satisfaction of, if I've had like 3 straight days of like having like 6, 7, 8's, I'm like "yessss, nailing it". And then like I feel good' (P4)

Experiences of hypoglaecemia

'Because I've been hypo I then feel rough for the rest of the day' (P2)

'Um, yeah, had fits in the night and she used to get the paramedics out and I'd get blue lighted through to hospital. And be very very poorly.' (P5)

'I lost my first warning state for my hypos. So, I'd go from like fine, to really not fine really quickly' (P1)

'I was walking home from school, (...) I got to the middle of the road, my friend went off and my mum phoned her up half an hour later and said where was I? They both came out and found me in the middle of the road because I'd collapsed hypo, (...) I don't remember it, I just remember being told about it, was scary, yeah. (P2)

'I used to, um, be so scared of having a fit during the night' (P5)

'Obviously like when, when I'm low I'll make very bad decisions and I'll be slow and annoying, you know, to be around. Uh, cos you haven't got the glucose in your brain so it's not working properly' (P4)

'It's affected exams and stuff, I've had hypos in exams, erm, and until I got special dispensation,' (P1)

'It does get annoying if you're low and then you can't go somewhere or do something because it's low and you have to wait for it to come back up um, it can get frustrating' (P2)

Feeling frustrated and restricted by treatment regimes

'Not having a lie-in, for, at least 10 years where I split my basal between 8am and 8pm and that was it, you couldn't do it at 7 or 9, you had to set your alarm for 8 o'clock and wake up and inject and then go back to sleep, and things like that' (P3)

'OK if I get up in the morning I have to have breakfast and I have to have lunch and, um, there was always that worry that if there wasn't a meal coming then I'd get really anxious about it' (P1)

'I was having to get up an hour earlier, cos you had, originally you had to have it an hour in advance of, eating. And you were only allowed certain things. So I had to have breakfast, then a mid-morning snack, then lunch, then a mid-afternoon snack, then dinner and then an evening snack.' (P7)

'I was doing two injections a day at set times, so I had to eat at set times and have snacks at set times. And set amount of carbohydrates so everything had to be weighed out. My potatoes, my rice, that sort of thing.' (P5)

'I do have to be quite careful about what I'm eating or how I'm feeling' (P1)

'If diabetes was to stop, today, um, I would probably still be looking at stuff for the next 10 years and trying to figure out the amount of carbohydrates.' (P6)

'I'm a hell of a lot more aware of what I'm eating. (...) that's a positive thing. Encouraging us to eat better. It has encouraged, it's encouraged me to eat better you know,' (P4)

'No, you go out for any kind of length of time it's you know, you've got your injection with you, you've got your blood test kit with you, and um, you know bit of Lucozade or dextrose tablets or something with you, yeah you just [sighs], you got to be prepared [laughs]. Because sometimes you could, you know even the best laid plans, you know, you've just gotta not be without those things really, well you shouldn't be without those things.' (P8)

'And that advance planning of, I can go away for a night here, because I know home's near. But if I'm going away from home, I have to make sure I'm organised with the medication. And make sure I've got more than enough. And food, and hypo food. Cos people that I go to may not have food that I like, or the food that, is, is like suitable.' (P7)

'It's more of a hassle (...) when, the pump needs to be changed every 3 days.' (P6)

'I know that like, as good as my, all my circadian rhythms and my carbohydrate ratios are, if I'm having, you know, a little portion of couscous and some lovely fried vegetables. That's going to work perfectly. But if I have a Dominos or a curry, even if I've got spot on ratios, it's going to be bugged.' (P4)

Additional health complications

'I do get um some problems with my leg, and they did say it was nerve damage' (P2)

'I had a massive bleed in one of my eyes. Um. And I couldn't see out of that eye (...) signed off work, 5 months later I had surgery to remove the clot. And then, a year later, the same thing happened in the other eye. So, for those 5 months, I completely lost my independence' (P5)

'Where I am today is, I've got chronic kidney disease, um, so it just results in a lot of tiredness. Um, I have diabetic neuropathy um so the legs, bottom half of my legs are just quite painful quite a lot of the time, and a lot of numbness when it comes to my feet. I've had some laser surgery done in both eyes [pause] and all this kind of happened, fairly kind of rapidly (...) So, all that happened and I, was put on to ill-health retirement from work. This time last year, so, yeah. I was basically assessed that I wouldn't be going back to work and that was that then.' (P8)

'It's scary losing your sight, losing one of your senses. You miss so much, you just, I got depressed. Um, just found life really difficult.' (P5)

'Yeah, so I think the background retinopathy, um, kicked it off just because I knew it was a sign of a long term effect. Um, and up until that point I'd not seen any of the long term effects. Um, that, you know, the long term side effects of actually having it. And at that point it was kind of a trigger point' (P6)

'I ended up having appendicitis, got rushed in with full DKA in intensive care for 3 weeks, and had about 2 months off college [pause] and I think that was my first like, holy crap there's no actually control over my body, appendicitis can cause this, and I think that scared me a lot.' (P3)

'Has developing the complications changed the way you feel about living with it?

[pause] Yeah, I mean it's all consuming. Diabetes is all consuming to me now.' (P8)

'I think it was probably around the time of the eye again. That was a massive shake up for me. Massive.' (P5)

Psychological impact of T1D

Psychological and emotional distress

'Because of everything that was going on it really affected my mood really negatively' (P1)

'The hardest thing I think has just been, the, yeah, that kind of psychological pressure that it's had on me.' (P4)

'I know diabetics are more prone to getting depression and I do go through phases of it.' (P5)

'I think it can be, I think it can be depressing when you think about all the stuff that's piling up against you.' (P6)

'I mean [pause] I, It's kind of there's a mood thing as well, I can get into some real downers about my situation because it can just really take you to really dark places sometimes I think.' (P8)

'When I was a teenager it really annoyed me at one point and got me down' (P2)

'It just frustrates me quite a lot' (P3)

'It's definitely given me a lot of like fear' (P4)

'I thought about the psychological effect having diabetes has had on me and I think the biggest impact has been the 'threat' that is always at the back of my mind. Sometimes it's very real and in the short-term (i.e., hypos) and sometimes it's the more distant worry (i.e., "how's my high blood sugar today going to affect my eyesight or limbs in 20 years time"(...) It's something that, for me, comes in ebbs and waves - it's always there, but sometimes it can induce real panic and fear' (P1 post interview via email)

'You know, it's um, it's, it's, it's not an easy thing to live with. (...) and being able to get that message across to people who don't live with it, that it isn't an easy thing to live with. Um. You know. Is important, I think.' (P6)

'It was difficult to verbalise my thoughts and feelings (...) I know from past experience talking about my diabetes in any depth would bring me to tears or make me really upset' (P1)

'So through things like that, that, the uh, uh, yeah the sort of negative stuff from the diabetes has got better. Um. Yeah, it's not like, it's not fixed' (P4)

Constant awareness and worry

'I think it's something you have to experience, I think you, you really need to kind of 24/7 7 days a week, (...) I just think you have to, whether it's the very fact that you have to inject or that you have to be aware of [pause] you can't switch off from being a diabetic, you can't forget about it' (P8)

'The nurses down the hospital, um, pitched it, err, visualised it, like an iceberg. You know, you got the tip of the iceberg which is your normal day to day stuff that you have to deal with, that everyone has to deal with. Um, you know, family issues, work issues, stresses, car problems, all that stuff. And then underneath the water you've got the rest of it, which is your diabetes. (...) knowing that there's so much underneath the, that level of the water, um, that can effect everything else that everybody else has to deal with anyway. I think it can be quite daunting.' (P6)

'Because that's always a constant thing that's running in the back of your mind, is oh what have I eaten today? What have I done today? What will I need to do?' (P1)

'It's this thing of it just wearing you down over time like a, yeah. All these tiny little moments where you have all these, uh, like problems because of the diabetes' (P4)

'But there is just so many little things, that just chip away at you over the years, you're just like, diabetes is a pain in the bum.' (P3)

'I suppose it was the feeling of always having to pay attention to how I felt and if I was going to be hypo' (P2)

'Because all you need to do is concentrate on work and you've got this other thing just kind of sitting there going right, is the blood sugar ok? Is it getting back down to where it should be?' (P6)

'Mainly to do with worrying about going low. Hypos. Uh, I've always felt, constantly just, in fear of uh. I guess it's a, a weird fear of embarrassing myself.' (P4)

'You've always got the thought of things could go wrong or the complications that could happen.' (P2)

'The long term risks of diabetes, that's always there as a thought' (P3)

'Quite a lot of fear about, health problems in the future. Um [pause], worrying about when I'm gonna, you know, kick the bucket because of it.' (P4)

'I'm scared of what's around the corner really.' (P8)

'Kids. Always on the forefront of my mind, because, (...) it's coming to that point in life, and then I just keep thinking if my diabetes isn't controlled, that can cause miscarriages, it can cause children to have disabilities, you know heart defects, everything (...) and then like, passing down the auto immune deficiency you know, you could have a diabetic child down the line and, that's a scary thought' (P3)

'Well, we had our first child (...) last year. Erm, [pause] and it's things like seeing him, grow. Seeing him grow up and thinking to myself, "I don't want him to be diabetic, but I know there's a chance of it." Erm, yeah I know there's a higher possibility that he could become diabetic because of me.' (P6)

'For the future. I'm worried a lot about having kids. Because I do want to have kids, but I don't really wanna have a kid and have it be diabetic. It's in my family. Err, I do kind of worry about that,' (P4)

'I got to a point, probably a couple of months later where I was like, it doesn't matter how hard I try, it's always going to be wrong, or there's always going to be something there that's going to get in the way (...) psychologically it's like, I'm trying really hard to do something but I can't do it so, um yeah it has quite a big negative impact in that respect. ' (P1)

'Maybe it emphasises the feelings of, can't control it, not worthlessness but that sort of thing, and just I'm not good enough type of thing, but it varies' (P2)

'Before I was managing it well, it was just like this constant little, sort of like reminder of, you're a failure. It's like, bad blood sugar, high blood sugar, low blood sugars, every day, like 5 times a day. It's like "you're an idiot, you're an idiot, you're an idiot, you're doing it wrong, you're an idiot, you're a failure", you know.' (P4)

'I mean there's been some very successful diabetics, but, I'm not one of them' (P8)

Behavioural impact of T1D

'But, um, but I do know that it affects my mood now. Whether that's, whether that's physical, whether that's just a psychological thing I don't know' (P6)

'Like the amount of times that I'll just snap at my husband for no reason, and I'll come back like, I'll go off and I'll check my bloods and I'll come back and, I know it's no excuse but my bloods are high, sorry.' (P3)

'Low or high blood sugar make me irritated and irritable and, you know, being maybe a bit of a nightmare to be around.' (P4)

'I just get moody, I get irritable, um grumpy I think. (...) and I do put that down to, just how you feel with your diabetes, if you don't feel great then you feel grumpy,' (P8)

'A friend of mine who was on his stag do and he was home by midnight. Cos he couldn't stand, or walk, or speak. Um, and I was the one taking him home because I was the sensible one out of everyone because I was the one that had to, you know, had other things to, to kind of think about. So. I think it makes you more sensible as well.' (P6)

'I was never a kid to bunk school or go off on random road trips on any hour of the night with friends with drink in the back of the car, in my mind like where are we going and what time because I need to make sure my insulin is going to be kept quite cool and I need to know where can get snacks from and are we going to eat today? [laughs]' (P3)

'In a way I guess it's like, uh, it kind of keeps me, more inclined to be like regular, not boozing and stuff, like that.' (P4)

'I think the, it can be a normal kind of frustration about, you know other people can just get up and go and just do whatever they like, but no I've got to think about injections and food, and no I've got to plan and I can't be so kind of "spontaneous" um, like the rest of the population can,' (P8)

'But they make it more difficult, because I can't just, go, let's go away to my friends for a weekend, if I don't have enough medication. Things like that. Sort of. I have to make sure I've got food on me, wherever I go. And spare insulin. And insulin pumps. And needles. And blood testing strips.' (P7)

'I suppose you could go with the flow more instead of having to always be prepared.' (P2)

Impact on development and sense of self

'I suppose the main thing was being different, and not wanting to be different wanting to be the same as everybody else. Um, the why me? scenario' (P2)

'So yeah, just felt different, didn't want to feel different. Wanted to just fit in and be the same as everybody else.' (P5)

'You just want to be kind of, like everyone else, and you can't be like everyone else, you're not like everyone else, you are [pause] you are a diabetic and you have to do the bloody injections or pumps as the case may be, um, and you can't forget about it' (P8)

'I felt that as a lot of my friends were going through this, or just, or a, anxious awkward phase, and kind of coming out the other end of it sort of better for it. I felt like, with me, it kind of almost, was the other, the opposite. I felt like I was becoming less confident about life as like a young person. Because of, noticing more and more, the diabetes, inhibiting my life. Holding me back, giving me anxiety and stress' (P4)

'I had a rebellious time sort of as a teenager at one point, and was very much, I can do anything anybody else can do. I used to go out with my friends at the weekends and eat sweets and my Mum could never understand why my sugars were high and I never told her until a few years ago' (P2)

'I just became really blasé with it. I was just like, aah yeah I can have a handful of chocolate it will be fine by dinner time, (...) I think in being blasé there was a bit of rebellion going on' (P3)

'As I went through my teenage years, I rebelled. I was like, it's not happening to me. I'd buy sweets on the way home, and eat them, without my mum knowing. Not do insulin for them. Um. Didn't test my blood sugars. Just really rebelled.' (P5)

'I'd just got together with my wife. We were engaged to be married. And I just, you know, the whole turning point in your life, you're kind of, um, you're kind of thinking, there's other priorities now and I want to be around for as long as possibly can.' (P6)

'Yes, I think probably with the maturity came the realisation that I had to work with it, rather than against it.' (P2)

'I think, just growing up's helped. Hmm, and priorities changing. (...) I think diabetes has made me grow up a lot faster, and I don't know if that's a negative or a positive, I like to think it's a positive, but, yeah. I think, I think that does help' (P3)

'Well it's hard to separate the diabetes from me as a person.' (P1)

'I don't see myself as the girl with diabetes. I'm just me.' (P7)

'I'm not frightened of it now. I accept that I've got it. Um, it's part of me.' (P5)

'I suppose nowadays I just accept it's part of me' (P2)

'it's always been a part of me' (P6)

'Diabetes is a part of who you are, it's, that's it, that is one of my biggest personality things, it's now become part of my life. It's part of me now' (P3)

Social impact of T1D

Perceived impact of diabetes on others

'It does affect relationships' (P6)

'If, you're talking about partners, my girlfriend, will have to put up with me kind of being a bit of a horror,' (P4)

'Cos, as a youngest, when you move out, your mum worries anyway. And then obviously with the diabetes it's that, more of an added worry for mum. I think she worries when I go out clubbing, because of the diabetes, and being female [laughs]' (P7)

'But yeah I know people are worried about how, if I'm going to be hypo and I keep getting told by my partner all of the time now, check your sugar levels see what they are, um and other people as well at times.' (P2)

'Yeah, difficult for my mum. Erm, I've got an older brother so she was working, looking after my brother and coming to hospital. Um, I felt a bit of a burden, to my parents. (P5)

'I think about it and I feel like 'oh I was such a nightmare, I feel so guilty' (P4)

'There's stuff that I've hidden from other people that, um, especially parents. (...) I've hidden stuff from parents because I didn't want them to feel that they put that many years into looking after me and then I went and [pause] screwed it up.' (P6)

'But yeah, it's a lot to do with not putting other people out and thinking it's my condition and not anybody else's to deal with but, I know it does have a knock-on effect on other people.' (P2)

Help and support from others

'With my Mum. Um, obviously she had been there since, she was there when I was diagnosed. Um, and she's always supported me in everything. Really has, she's the only one that understands what I've been through.' (P5)

'My husband's really good with it. When we first got together, he printed off a 200 page, in a ring binder all about diabetes and side effects and help sheets and he had a little draw by the side of the bed where he kept sweets and my spare blood meter in and, um, I think that, feels as though, in some ways you know that people are accepting it more and are there to support you.' (P3)

'My girlfriend has helped me a lot. Because she's like, this really good voice of reason that I don't have in my mind.' (P4)

'I had a very good group of friends that all learnt how to do my blood sugars. All learnt what needed to be done. All learnt like, all had my mums number just in case. Things like that. So I had them as a group. Kind of, it wasn't so daunting. I think if I'd been on my own, it might have been.' (P7)

'Everyone knows I'm diabetic at work. Um. You know, it's not like I keep that sort of thing hidden. It's pointless hiding it. You know, um. Everyone's pretty, pretty ok if I turn round and say I need to go get something to eat. They're fine about that. Um. [pause] And, and, they know I'm argumentative sometimes [laughs]' (P6)

'But, the secretary there her husband's diabetic so, um, she understands and is quite willing to help if needs be' (P2)

'When I was working I made sure, I think pretty much everyone knew that I was a diabetic, and, you know I, there was kind of no issues, everyone knew I was diabetic and I'd do blood tests in front of people and, yeah, I did at my desk I didn't go to the toilet for instance and do it.' (P8)

'I think uh people's perceptions and people's understanding of it is better now' (P5)

'I think people's knowledge has got a lot more.' (P3)

'I think, it's becoming more, common. People are seeing it more, so they'll understanding it more.' (P7)

'Like, everyone kind of knows, is aware of it and it sort of just, present, and vocalised. That has made me, be more, I guess more active with it. (...) it's just because it's, gives it like a sort of, normal, err, like feel to it' (P4)

'So, yeah and asking for help and accepting help is really difficult. But at the same time I really want it, and now I'm really aware, I still want them to go, you know, are you alright? so, yeah, balancing those two is, difficult.' (P1)

'I think now it's the fact like you know, I'm married have a house, I no longer have people, anyone to fall back on, this is now me standing on my own, you know, don't have the family support or the, you know, that's it really, I've got to, pull my finger out' (P3)

'I think one of the hardest things was having to deal with it yourself [laughs]. Um, you know when somebody else was taking care of it, it's nice and easy. When you're having to take care of it yourself, it's a very different kettle of fish. Yeah.' (P6)

Stigma and lack of understanding from others

'You always feel like you're on your own and nobody else quite understands' (P2)

'I've often said that people who aren't diabetic should be diabetic for a year, and just so that they, they get it (...) No one really gets it. Um, you know. It's not them that's having to face this for the next 50 years. 40 years maybe, who knows. But, you know, it's not them that's having to look at that.' (P6)

'Obviously you've got the whole diabetes team of like ridiculous amounts of people around you, but none of them are diabetic. (...) I don't think anyone apart from a diabetic will ever understand,' (P3)

'I, even now, I find the, lovely as they are, the diabetic doctors and nurses, great. But. They're not diabetic themselves. They don't live with it day in day out. They don't have the frustrations of why's my blood sugar high when I have done the right amount of insulin? Or, you know. (P5)

'healthcare professionals can say, ah you can do this, you can do that, well your blood sugars too high, your too low or, but I'm not being funny, you need to be a diabetic to truly understand diabetes.' (P8)

'If you're hypo it's difficult for other people to sort of understand and some people I think are very scared of you going hypo all the time, more so than I think we are ourselves' (P2)

'A lot of people don't understand the actual sensation feelings that you're going through, a lot of people now, they have the knowledge, they know what diabetes is, but I still to this day can't describe to a non-diabetic, the feeling of going hypo. (P3)

'People don't understand how, you know. You understand how sweaty you get when your blood sugar drops quickly and, you know. How irritable you can get, and, and, for no reason. And, or, there's, for the tiniest little thing can just set you off' (P6)

'People always kind of talk about type 2 diabetes which is, yeah, lifestyle, so you know it's thought of you kind of brought it upon yourself, so it's not a worthy cause to, it's not thought of as a worthy cause. I think type 1 gets caught up in that really.' (P8)

'My biggest bug bear, is the generic "Oh did you eat too much sugar as a kid?" or "Ohh, is it because you were overweight?" and I'm like Noo, stop just, you have no idea, because everything is about type 2, people don't know it' (P3)

'Or I've had "oh, but you're not fat". Yeah I know! [Laughs] Cos I'm not type 2. There's no, understanding from, I think, members of the public and the hospital between the two differences.' (P7)

'One of the annoying things is the misconceptions about, um, or the misunderstanding about the differences between diabetics. You kinda get bundled under type 2 and you, you kinda just get bundled under a diabetes umbrella. You know. And people don't realise that 90% of diabetics are actually type 2, and that, type 1 is, you know, you can't do anything about it, it happens. It's one of those things' (P6)

'But it's then when you've got like jokers at work and things that are just like, "ooooh you're one of those diabetics" and I'm like, that's just not settling well with me because actually this is part of who I am,' (P3)

'Secondary school, um, they wanted me to go to the first aid room to inject. And I refused. I said "I'm not doing it". I'm not, I'm not giving up my lunch break to come and inject, for you to supervise me, to check what I'm doing with the needles. I'm not leaving them around. And so I kind of felt like I was a drug addict, like they would, that's how they were treating me.' (P7)

'Um, I remember having hypos in classes before, and people, there was one boy in particular, still remember his name, taking the micky out of me and being really nasty to me.' (P5)

'Me and my brother and a few friends, (...) went to a pub of an evening. And, I think I was going to do my night time injection and a member of staff came over and said, can you do that in the toilets, don't do it where everybody can see. Isn't that encouraging bad drug users to use the toilets rather than actually having people ask and then obviously I'd answer but she didn't believe that I was diabetic and that was (...) quite upsetting as well because it's like I didn't like the way it was done at all' (P2)

'I don't think people realise it can be as, dangerous, as it can be. If that makes sense? Yeah, it, it can turn quite quickly and it can be dangerous. People don't realise that. They see it as 'oh you just eat sugar'. Or 'you shouldn't have sugar'. (P7)

'So I do still think a lot of people think diabetes is less than it is.' (P3)

'It's one of those, um, what do they call them? (...) Unseen conditions, yeah. It's one of those things, where people just go 'oh, you look fine'. Yeah, I really don't feel fine [laughs]. Um, you know, and people don't understand' (P6)

'I remember thinking I had to stay in, because, if anyone from work sees me, they're gonna think that I look fine, because, looking at me you couldn't see that there was anything wrong with my eye cos all the blood was on the inside.' (P5)

'People need to know, to know I need help. So, I had the other day, 'but you don't look diabetic, you look very well for being diabetic'. I'm like, 'yeah, cos I've worked hard at this. You normally don't look ill unless it's the beginning of the diabetes or you've got problems' [laughs].' (P7)

Influence of healthcare teams

Support from the diabetes team

'Long story short. They're excellent.' (P6)

'Really recently they've been a great team for me,' (P3)

'But I know that if I phoned them up then they'd say come in and talk to us. Um. Yeah, I know the support is there if I want it.' (P5)

'The diabetic nurse and as I say I see her three or four times a year um she's very good' (P2)

'My diabetes nurse is my rock' (P3)

'She was kind of awesome. Like, yeah she, was like, just, there was so much more communication. And I felt like we were, I felt like, I felt like she was really looking to understand, me, and how she could help me manage the diabetes better' (P4)

'Um, My nurse, in particular will make me look at the sugar levels, a lot of the time she'll ask me what I think, I should do, and, er probably 50/50, I know what I need to do but I'm not quite sure how to do it, or well no, most of the time I know what I need to do or I'll tell her and she'll just agree. So I suppose it's reassurance, is a key thing for me' (P2)

'Things like they're not just handing it to you on a plate, they're making me kind of think and they're supporting me doing it' (P3)

'Absolutely fantastic during pregnancy. Um, it, I had to go there every two weeks, which was a pain. But support from them was amazing.' (P5)

'They were good, the, the, the nurses were good when I moved onto the pump, they were very helpful' (P4)

'And I think, they obviously want me to call up at the moment because I've only just switched over to a pump, or, just, being within the past year, but. They're like, you know, 'just give us a call if you need anything'. Um, so, they're really good.' (P6)

'I have more, health care check ups. Which I guess, is a positive. Because things can be seen, earlier, if there are any other complications. Like, if I, hadn't have had all my check ups, they wouldn't have found that I had high cholesterol. Because it's not from the diabetes. It's hereditary.' (P7)

'And the diabetic team I suppose the reassurance of the other tests that they do like the cholesterol,' (P2)

'When you've worked hard and when you have put out a lot of effort to try and get your bloods down and to control them, and it's just the reassurance of them saying "you're controls better" and "well done, we noticed this" and it's just the little pat on the back sometimes that they give you,' (P3)

'Um, whereas, again, down here um, they're very, they were very kind of 'we know. We know that people didn't look after and don't look after themselves at points in their life, we know that it's hard work'. (P6)

Difficulties with the diabetes team

'What role does the diabetes team have in your life at the moment?

Err, right now. Not a lot. I see the consultant once a year (...) but it's never regular contact (...) there's not a lot of support there I guess (...) I'm sure they do lots of stuff but I just don't, I'm not in contact so I don't know it, or know them at all.' (P1)

'Years ago, I didn't, didn't really have any diabetes teams involved. They weren't really, overly helpful.' (P6)

'For me, I can't think of anything to be honest, because I [pause] I don't know what they can do for me to be honest.' (P8)

'Maybe it's just because I don't, really relate, I don't feel like we really communicate properly.' (P4)

'I had a bit of a, dodgy, kind of, diabetic nurse. Who I didn't really, get on with. I used to hide from her, when she came to the house. Um [pause], I just, she was very harsh. There was no kind of, compassionate, care of, let a child get her head round everything. It was "this is what you are doing, this is how you should be doing it". It's like, 'ok I get that, but, let me get my head round it first'. (P7)

'In kind of my, my teenage years there used to be a district nurse or diabetes nurse who used to come round our house and would kind of harangue me for, not being as well controlled as I should, (...) she'd just come round and come and check me out, and find out I wasn't doing as I was told so she would tell me off.' (P8)

'Every time I went to the hospital for check-ups I got told off for the high blood sugars, and I, come teenage years I was just like I don't need this hassle, go away, and, um, I'm doing my own thing.' (P5)

'When I went round to see, went down to see him. Um, so, but he made you feel like, he made you feel like, you know, 'well you haven't done this therefore you're a bad diabetic' sort of thing.' (P6)

'I've always gone up and down, but made to feel like it's my fault, from the diabetes team. Even when you prove, like, it's like, "well, what are you doing?". It's like, you can see what

I'm doing, I've given you a food diary. I'm not hiding anything, cos I'm pretty honest, I will tell you if I've done something wrong. (P7)

'OK, if you, even if you haven't done as well as you should have, if they can talk to you about it in a kind of nice kind of adult manner, instead of maybe treating like a school boy or something, then you know, they may get more out of you and persuade you to improve things.' (P8)

'You go there and you wait at outpatients and you queue up and you re-book your appointment for a day you know you can make it, and then 2 weeks later you get a letter through the post saying we had to move your appointment,' (P3)

'And frustrated at the hospital because, last time I forgot one was because they'd actually cancelled the one before because my consultant had retired and they didn't tell, well they did tell me they'd booked a new one but I didn't get the letter,' (P6)

'They either get cancelled or, you're waiting for hours and hours and hours and hours' (P5)

'There's always a wait. You go for your appointment and you're there like an hour later still waiting for him. But they expect you to wait. They expect you to do that, even though, like, you might take time out of work' (P7)

'Hospitalisation with DKA. That was tough (...) that was quite a difficult time. Just the whole, getting my head around that, and you know afterwards they send you to a shrink (...) they just said, we think it would be beneficial for you to go to this shrink, here's an appointment. (...) I went to shrink and after the like 2nd, the 1st week it was just like a get to know me type thing, and the 2nd week I went, I was in floods of tears, for like 20 minutes, and he didn't mention my diabetes once (...) and I think at the time I asked him a question on diabetes and he didn't know, he didn't have a clue what diabetes was (...) So I stopped going, because I was like I'm not going to talk to you about unrelated matters which to me don't mean anything when actually, you don't have a clue about diabetes, which is why I'm here in the first place.' (P3)

Attending carbohydrate counting courses

'And then I did the DAFNE equivalent course, which was great. That was, to be honest, I think that was the best thing I've ever done, positively, for turning the diabetes around.' (P4)

'I think one of the best things that's happened in the last few years, um is there's a course that the hospital (...) Which was a fantastic er, um course really.' (P8)

'Well they did the DAFNE course, and that was really helpful. (...) it just gave me information that, I didn't have, really basic stuff that should be compulsory. Umm, and I think that the GPs and consultants just assumed that I knew, that, they might have told us but I don't remember. So yeah, really good to have all that information really.' (P1)

'And I got all these skills about carbohydrate counting and then I starting getting, like feeling better about it I think' (P4)

'Once we were given a ratio of units and carbohydrates, um, I stopped feeling hungry all the time, and that was, quite a big shock, anyway, because I just thought it was normal to be hungry all the time, so that was really good.' (P1)

'I'd say, one of the biggest things, and actually even though I didn't realise it at the time, um, after join, after doing the (...) course was that there is actually other people out there who go through the same crap. Um, who deal with the same thing day in day out. Um, who, have been through the same thing you've been through' (P6)

'One of the really good things, there was a group of eight of us, (...) um and, yeah how we, how people would talk about well my blood sugar was like 6 and its gone up to 15 there and I don't know why, and then you sometimes do an injection and, you know to counteract that and, the next minute I'm getting a hypo, and, you know people, what I'd call sane sensible people would struggle and, and I thought I'm not alone here, I felt it was with other people that truly understood' (P8)

Simplistic view of diabetes

'So, it's almost like the teams have always felt that, diabetes is black and white. But it's not. And like, obviously you get the text books about diabetes. And they seem to follow that. And they don't seem to look at you as an individual as to why you might, be up and down, or things like that' (P7)

'I kind of sometimes wonder that, the amount of people they churn through, worries me a bit (...) there's only so many people that they can actually know through and through' (P3)

'Sometimes I feel like the nursing, the quality of the nursing is maybe slightly just sort of, uh, follow the training and just, do the stuff that you've kind of been taught, rather than, talk to me and really kind of find out what, what, what we could do to improve things.' (P4)

'And I just think, to a certain extent, you're a doctor/nurse telling me you need to this, you need to do that, you need to do the other. Actually, don't patronise me, because you don't live with the condition. You don't know, one day, you can eat the same thing, do the same amount of insulin, perfect control. Next day, you eat exactly the same, do exactly the same and it's up there or down there' (P5)

'Most of the time I'm, between 12 and 17 and if my HbA_{1c} is still coming back good that's not, there's something not matching up there and that is what they look at,' (P1)

'Especially when I feel sometimes mostly my sugars are high or not controlled very well and then the diabetic team say they are fine, it's like, it's not fine, I'm not happy with them but, they generally are,' (P2)

'I can't help but think that diabetes is such an immensely complicated disease to medicate. You've really got to like look at why a blood, you can't just look at like a few days of blood sugars and be like 'let's make these changes',' (P4)

'You just see a doctor that's a, yep, yep, yep, yep, ok you're fine. It's more of a process I think. I find the help from the diabetes team, the diabetic centre, much more valuable than my annual reviews.' (P5)

'I feel like, I've never had any, real help with the system, the sort of, the, the health system around diabetes at least for um, the emotional side of this disease. Which I think is like, you know, equal the getting the blood sugars sorted out, it's just as important.' (P4)

'The psychological effect having diabetes has had on me and I think the biggest impact has been the 'threat' that is always at the back of my mind (...) I feel it's something that is definitely missed and trivialised by not only the people surrounding diabetics but even the medical staff and team trained to work with you' (P1)

'But they just seem to have like a, nonchalant attitude in A&E as far as I'm concerned, and as far as I've witnessed. So, I think, a, a better understanding. Not, as extensive as the diabetes team, or as in depth. But a greater understanding and not just what they read in a text book. Because I've had paramedics, I've had a paramedic come out and goes 'I don't know anything about diabetes'.' (P7)

Ways of coping

Discussing diabetes

'I do always like talking about it. Cos it's like a nice sort of, offload' (P4)

'I think actually talking to other diabetics is quite a good thing, because you always feel like you're on your own and nobody else quite understands but, there is a lot of people that do' (P2)

'Knowing other people out there have kind of gone through it and there are people out there who feel the same. And all the rest of it. That's, that, that helps. Helps massively' (P6)

'I set up a support group (...) We've all found it reassuring that there's other people out that go through the same feelings and frustrations and thoughts and worries, and you're not on your own' (P5)

'My own therapy has allowed me to learn coping mechanisms' (P1)

'So I've had CBT and that's helped me control my anxiety in relation to that, but also in relation to everything else because I can now recognise the signs of anxiety and I can, I can manage them' (P5)

Technology

'Things like Facebook make that easier. Join groups. That helps. Um, because there's always someone looking around for articles and latest and greatest stuff. Um.' (P6)

'More stuff's out there, that makes me think actually, I'm not the only one (...) like if you've got any question you can type it into Google and within 20 seconds, you can see like 100s of

other diabetics around the world who are asking the same question, and I think that at least for the first 10 years of my, having diabetes that wasn't available,' (P3)

'The new equipment, the technology has got so much better over the years,' (P2)

'Just the advance in technology. Um, even from when I was first diagnosed, it was syringe and insulin vials. Then I went onto pens which made it a lot easier, um, and now as I say I'm on a pump which, I got, control, I can do point, point one of a unit, now. Um, which was great' (P5)

'So I'd probably say the things that have made it better have been technology more than anything else,' (P6)

'Since I've gone on the pump, my diabetes has improved. I'm more kind of, steady.' (P7)

Not thinking about or engaging with diabetes

'I guess a lot of my life I haven't really thought too much about the diabetes. I just tried to live [pause] as, I tried to live as everybody else has lived, and, did what I wanted to do rather than what I should have done.' (P8)

'The main thing has been not making a big deal out of it, I think for me so that I still feel normal, I think. (...) and on the flipside of me trying to be normal is that sometimes, I could potentially be in a dangerous situation because people didn't realise the gravity of a hypo, or even know that I was diabetic, or know what to do if I needed help so, from a safety point of view, it probably wasn't that good' (P1)

'I was just like, you know. Slightly, indifferent towards it, I didn't, I think.' (P4)

'I hadn't really looked after my diabetes properly while I was growing and (...) just wanted to just ignore it and bury your head in the sand.' (P6)

'I hardly tested, I hardly did, I just did the set amount of insulin that I had erm and I didn't really think about it. I didn't, [pause] I don't remember really thinking about it,' (P1)

'I wasn't going to the hospital appointments much.' (P4)

'Um, there were nights I didn't bother doing long acting insulin because it was either painful or, um [pause] or because I just, just didn't want to. I don't like, I wouldn't be able to tell you what was running through my head 20 years ago now, when I was thinking "I'm not going to do it tonight'." (P6)

Accepting and engaging with diabetes

'Nowadays I just accept it's part of me and I have to work with it more than against it, and that's yeah that's a big thing' (P2)

'So I kind of say to myself 'I'll never, what's the point of ignoring the diabetes when it's there for the rest of my life'. I might as well work with it, to kind of, get the most out of my life and, what I want.' (P7)

'Actually I've just got to embrace it because otherwise I'm screwed, I'm stuck with it anyway.' (P3)

'I'm not frightened of it now. I accept that I've got it' (P5)

'I just sort of decided I'll have to take it day by day because I was testing my bloods all the time, and it became, like yeah just too much,' (P1)

'You know, I might end up in a wheel chair. Or I might end up having a heart attack, pfff, don't know, don't think about it. Um, I just take each day as it comes really.' (P8)

Hope and positivity

'I've never ever let it stop me doing anything.' (P7)

'I try not to um, full stop, let any more, use, use the diabetes for an excuse, for anything.' (P4)

'A lot of things have changed over the years already there's still time to make a lot of improvements.' (P2)

'Sometimes, if my sugars are a bit low I get to have a chocolate biscuit which I quite like [laughs]. You've gotta have those little micro rewards to keep you sane I guess' 9P4,

'I don't know if there is anything actually positive from being diabetic, but I think there's a lot of positives you can make, whilst being diabetic if that makes sense? So, making yourself positive situations, because, it's who you are' (P3)

'I'm quite a positive person with diabetes. [Laughs] Cos I kinda have to be. I'm a positive person anyway.' (P7)

'And the research that's being done. I know they've been talking about islet transplants and all sorts of things. I think that's fantastic if they can do it' (P5)

'you know you're always hear, there was, there was a sort of, break through, news story about the, the, the stem cells, err, work that, it's maybe leading to a cure for the diabetes and they'd done it in mice and stuff. And you, and you hear things about cures all the time. Obviously that would be great, I do sometimes think about that. Err. So there is a bit of like, hope, for the future.' (P4)

'I think that was a tough moment, but you know I think I turned that around and made it out stronger.' (P3)

'I think I've been through a lot with the diabetes which I think has made me stronger as a person. I think I've learnt from it and I think I want to help others. I think that's a positive. And I think that I've coped with a lot.' (P5)

Appendix O: End of study report for NRES committee and R&D departments

Salomons Centre for Applied Psychology
Canterbury Christ Church University, Runcie Court
Broomhill Road, Tunbridge Wells
TN3 0TF

Dear Research Ethics Committee,

Study Title: **Exploring the experiences of people living with type 1 diabetes and their implications for psychological support.**

REC reference: **14/LO/1236**

I am writing to inform you that the above study has now been completed. Please find attached a brief summary of the research findings. Please do not hesitate to contact me if you require any further information.

Yours sincerely,

Michael Wilding

Trainee clinical psychologist

CC: [REDACTED] NHS Trust R&D
[REDACTED] NHS Trust R&D

Summary of Research

Study Title

Exploring the experiences of people living with type 1 diabetes and their implications for psychological support.

Research Context

Living with diabetes can present a number challenges for individuals concerned. Managing diabetes day to day involves a complex medication and behavioural regime which interrelates with various important psychosocial factors. Previous research suggests that people living with diabetes are as much as two-three times more likely to experience mental health difficulties compared with the general population. However evidence is emerging that many of these difficulties may in fact be a direct result of feeling distressed about living with a complicated and stressful chronic health condition, and not necessarily resultant from co-morbid psychiatric illness. These experiences are known by the term diabetes related distress. To date psychosocial factors related to living with diabetes have mainly been explored quantitatively. However, qualitative approaches have increased in popularity in diabetes research in recent years and can add valuable and rich information to existing data from quantitative research. Extant qualitative research in diabetes has mainly focused on people living with type 2 diabetes or children with type 1 diabetes, leaving adults living with type 1 diabetes as a relatively under researched group

Research Aims

The study aimed to answer the following research questions:

- Primary: What are the lived experiences of adults with type 1 diabetes?
- Secondary: What aspects of living with type 1 diabetes are experienced as distressing?
- What are the potential implications for health services?

Method

Eight adults living with type 1 diabetes were interviewed about their experiences. Interviews were transcribed and analysed using interpretative phenomenological analysis.

Results

Many themes emerged from participants interviews. Some example themes are; Feeling frustrated and restricted by treatment regimes, psychological and emotional distress, constant awareness and worry, impact on development and sense of self, stigma and lack of understanding from others, support from diabetes team and experiences of a simplistic view of diabetes.

Implications and Conclusions

Participants reported a wide variety of experiences related to the biological psychological and social components of type 1 diabetes. Some of these were experienced as highly distressing whilst others were more easily managed. This was often dependent on individual differences and was not necessarily static over time. Further awareness of this in practice and a focus on diabetes and its treatment within the context of people's unique psychosocial circumstances is highly important in supporting people to reduce diabetes related distress, which can improve glycaemic control, health related quality of life and wellbeing

Appendix P: Author guidelines from journal chosen for publication - Diabetic Medicine

Retrieved from: <http://onlinelibrary.wiley.com/journal/10.1111/%28ISSN%291464-5491/homepage/ForAuthors.html>

1. ABOUT DIABETIC MEDICINE**Aims & Scope**

Diabetic Medicine, the official journal of [Diabetes UK](#), is published monthly in simultaneous print and online editions.

The journal publishes a range of key information on all aspects of diabetes mellitus and issues regularly include original articles, reviews, reports, editorials, comment, news and correspondence. All material is peer-reviewed. The journal seeks to provide a forum for the exchange of information between clinicians and researchers worldwide and all health professionals responsible for the care of patients with diabetes.

Surplus generated from the sale of Diabetic Medicine is used by Diabetes UK to care for, connect with and campaign on behalf of all people affected by and at risk of diabetes.

2. MANUSCRIPT CATEGORIES

Diabetic Medicine invites the following types of submission:

Research articles

Original research articles relevant to diabetes mellitus science and practice are the journal's primary mode of communication. Clinical science and clinically-relevant basic science papers will be considered. Original articles must include a structured abstract (maximum 250 words), should not exceed 3,000 words of text and should be limited to 30 references. Inclusion of supplementary materials in the form of underlying datasets, multimedia files or accompanying slidesets is encouraged.

Authors of qualitative research articles are advised to contact the Editorial Office for guidance on manuscript length prior to submission.

Manuscripts should adhere to reporting standards. Randomised controlled trials should adhere to the [CONSORT Checklist](#). Observational studies should adhere to the relevant [STROBE Checklist](#). Systematic reviews and meta-analyses should adhere to the [PRISMA Checklist](#). Checklists must be completed and submitted electronically with the manuscript using file designation 'Supporting Document NOT for Publication'.

For purposes of presentation only, accepted research articles are divided into the following sections:

Care Delivery
Complications

Educational and Psychological Aspects

Epidemiology

Genetics

Health Economics

Metabolism

Pathophysiology

Treatment

Reviews

The journal aims to publish concise, high-quality review articles of recent advances in laboratory or clinical research. Review articles are usually solicited by the Editor-in-Chief but unsolicited reviews are welcome. All will undergo peer-review. Review articles must include an unstructured abstract (maximum 250 words), should not exceed 5,000 words of text and should be limited to 50 references. Use of illustrations and figures is encouraged.

Trial protocols

Diabetic Medicine now welcomes submission of trial protocols. Manuscripts must include a structured abstract (maximum 250 words), should not exceed 3,000 words of text and should be limited to 30 references. Inclusion of supplementary materials in the form of underlying datasets, multimedia files or accompanying slidesets is encouraged. For trial protocols of health care interventions, the last section of the abstract should be Trial Registration: listing the trial registry and the unique identifying number, e.g. Trial Registration: Current Controlled Trials ISRCTN73824458. Please note there should be no space between the letters and numbers of the trial registration number. The trial registers that currently meet all of the ICMJE guidelines can be found at http://www.icmje.org/faq_clinical.html. Publishing your trial protocol in *Diabetic Medicine* does not commit you to submitting subsequent reports of the study to us, although we do, of course, welcome such submissions.

Short reports

Concise reports of original or important observations, short reports should not exceed 1,500 words and are limited to one figure, one table and 20 references. A structured abstract is required.

Case reports

Case reports submitted after 1 May 2012 will be published online-only in *Diabetic Medicine*. The abstracts of case reports will continue to be published in the relevant print issue. Case reports remain fully citable and will continue to be indexed by PubMed.

Case reports should describe unusual clinical cases and must carry a new or important message. Cases that present a diagnostic, ethical or management challenge, or that highlight aspects of mechanisms of injury, pharmacology or histopathology are deemed of particular educational value. Descriptions of a series of cases stand a greater chance of

being accepted. The Editors reserve the right to ask authors to revise a single case report into a Letter to the Editor.

Case reports should not exceed 1,500 words and are limited to 3 tables and/or 3 figures and 20 references. A structured abstract (maximum 250 words) must be provided using the following sub-headings: Background, Case Report, Discussion. The submission of supplementary materials (additional figures, tables, datasets, multimedia files, etc.) which add value to cases is encouraged.

Letters

Items of correspondence may be in response to issues arising from recently published articles, or short, free-standing pieces expressing an opinion. Letters should be formatted in one continuous section and should not exceed 800 words, 1 figure/table and 10 references. No abstract is required. Please give the name(s) and affiliation(s) of authors at the end of the letter. All letters are subject to peer-review.

Editorials/Commentaries

Editorials and commentaries provide expert opinion to hot topics. Whilst typically commissioned by the Editors, unsolicited submissions are welcome. Editorials and commentaries should not exceed 1,000 words and 10 references. No abstracts are required.

3. SUBMISSION OF MANUSCRIPTS

All submissions must be made online at the [Diabetic Medicine ScholarOne Manuscripts site](#). New users should first create an account. Once a user is logged onto the site, submissions should be made via the Author Centre.

A [Submission Checklist](#) is available to help authors comply with the journal style and the submission requirements.

4. PREPARATION OF MANUSCRIPTS

Manuscripts must be written in English.

Manuscript text must be saved in Word (.doc or .docx) or Rich text Format (.rtf). Please do not submit text in PDF format (.pdf).

Figures must be saved as separate figure files.

Abbreviations must be defined when first used in the abstract and in the main text, as well as when first used in table and figure captions.

Manuscripts must be as succinct as possible. Repetition of information or data in different sections of the manuscript must be carefully avoided. Text must comply with the word limits defined in Section 2, and, where appropriate, include:

Title page

The first page of all manuscripts should contain the following information:

- 1) the title of the paper (maximum 50 words)
- 2) a running head not exceeding 75 characters
- 3) names of authors as initial(s) followed by surnames
- 4) names of the institutions at which the research was conducted, clearly linked to respective authors
- 5) name and email address of corresponding author
- 6) manuscript word count
- 7) a statement of all funding sources
- 8) any conflicts of interest disclosures (see Section 5)
- 9) a bulleted novelty statement (maximum 100 words) which describes the novelty of the data presented and their impact on the field (Research Articles, Short Reports and Case Reports only).

Abstracts

Authors submitting research articles and short reports should note that structured abstracts (maximum 250 words) are required. The structured abstract should adopt the format: Aims, Methods, Results, Conclusions.

Structured abstracts for case reports should adopt the format: Background, Case Report, Discussion.

Abstracts should contain no citations to previously published work.

Review articles require abstracts but they need not be structured. Letters do not require abstracts.

Text

This should in general, but not necessarily, be divided into sections with the headings: Introduction, Patients and Methods, Results, Discussion, Funding, Conflicts of Interest, Acknowledgements, References, Tables, Figure Legends.

Tables & figures

Tables and figures should not be inserted in the appropriate place in the text but should be included at the end of the manuscript, each on a separate page.

Tables and figures should be referred to in text as follows: Fig. 1, Figs. 2–4; Table 1, Table 2. Each table and/or figure must have a legend that explains its purpose without reference to the text; legends should include keys to symbols and indicate the statistical significance of differences. Where a figure has more than one panel, each panel should be labelled in the top left-hand corner using lower case letters in parentheses, i.e., (a), (b), etc., and a brief description of each panel given in the figure legend.

Colour illustrations are welcomed and all colour is published free of charge to the author.

Authors are themselves responsible for obtaining permission to reproduce previously published figures or tables. When an individual is identifiable in a photograph written permission must be obtained (see Section 5 below).

Figure requirements

Figure files should be provided in high resolution .eps format, minimum 800dpi (for graphs and charts) or .tiff format, minimum 300dpi (for photographs or a combination of images and text). Figures with multiple parts (A, B, C) or images should be provided as separate files. Do not copy and paste figure files into the manuscript word document.

If you no longer have the original data to improve/recreate graphs, charts or combination figures to high resolution, please crop the graph area in Microsoft PowerPoint and re-type all text and numbers in the figure. Text should be Arial or Times New Roman in minimum 14pts. Any lines in the figures must be at least 1.5 or 2pts thick. We accept .ppt files.

For more information on file requirements, please refer to http://authorservices.wiley.com/prep_illust.asp.

References

References should be in Vancouver format and appear in the text as consecutive numbers in square brackets, e.g., 'in our previous reports [1,2] and those of Smith et al. [3–6]' and should be listed numerically in the reference list at the end of the article.

Format references as below, using standard (Medline) abbreviations for journal titles. If multi-authored, include the first six authors followed by *et al.*

1. Department of Health. The New NHS: Modern, Dependable. London: The Stationery Office, 1997.
2. Fogari R, Mugellini A, Destro M, Corradi L, Lazzari P, Zoppi A et al. Losartan and amlodipine on myocardial structure and function: a prospective, randomized, clinical trial. *Diabet Med* 2012; 29: 24–31.
3. Eye Care Wales. Screening for Diabetic Retinopathy. March 2009. Available at <http://www.wales.nhs.uk/sites3/page.cfm?orgid=562&pid=12776> Last accessed 1 January 2012.

Reporting standards

Manuscripts should adhere to reporting standards. Randomised controlled trials should adhere to the [CONSORT Checklist](#). Observational studies should adhere to the relevant [STROBE Checklist](#). Systematic reviews and meta-analyses should adhere to the [PRISMA Checklist](#). Checklists must be completed and submitted electronically with the manuscript using file designation 'Supporting Document NOT for Publication'.

Style guide

Diabetic Medicine does not recognise the term 'diabetic' as a noun. Preferred style is 'people (or person) with diabetes' or 'in the group without diabetes', rather than 'diabetic people (or person)', 'diabetic patient' or 'non-diabetic group'. The terms 'Type 1' and 'Type 2 diabetes mellitus' (abbreviated to Type 1 and Type 2 DM) are preferable to IDDM and NIDDM. 'Men' and 'women' should be used in preference to 'males' and 'females'. 'Participant(s)' or 'person'/'people' is preferred to 'patient(s)' or 'subject(s)'.

Abbreviations & units

Except for units of measurement, abbreviations are strongly discouraged. Avoid abbreviations in the title of the manuscript and in the Abstract. The spelled-out abbreviation followed by the abbreviation in parentheses should be used on first mention unless the abbreviation is a standard unit of measurement.

SI units must be used throughout except for blood pressure (mmHg) and haemoglobin (g/l). Gas or pressure values should be given as mmHg with kPa in parentheses or vice versa. Where molecular weight is known, the amount of a substance should be expressed in mol or appropriate subunit (mmol). Energy should be expressed in kcal or joules (J). The solidus may be used in a unit as long as it does not have to be employed more than once (e.g. mmol/l is acceptable), but ml/min/kg is not acceptable and should be replaced with ml min⁻¹ kg⁻¹.

HbA1c Measurement

Diabetic Medicine has adopted dual reporting of glycated haemoglobin (HbA1c) measurement. HbA1c measurements must be reported in IFCC units (mmol/mol - no decimal point) in addition to derived NGSP units (% - one decimal). IFCC units should be listed first followed by NGSP units in parentheses. A HbA1c conversion table is [available here](#). NGSP SD's can be converted directly to IFCC SD's. To do so the slope of the Master Equation to convert NGSP results to IFCC units must be used. For example: 0.3% SD NGSP = $0.3 \times 10.93 = 3.3$ mmol/mol SD IFCC (then round to the nearest integer).

5. DECLARATIONS & PUBLICATION ETHICS

Original publication

Submission of a manuscript will be held to imply that it contains original unpublished work and is not being submitted for publication elsewhere at the same time. The author must supply a full statement to the Editor about all submissions and previous reports that might be regarded as redundant or duplicate publication of the same or very similar work. Data that have been published as an abstract of no more than 300 words in a scientific meeting are acceptable; the abstract reference should be quoted under the abstract.

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Authorship

All persons designated as authors should qualify for authorship and all those who qualify should be listed. Each author should have participated sufficiently in the work to take public responsibility for appropriate portions of the content. One or more authors should take responsibility for the integrity of the work as a whole, from inception to published article. Authorship credit should be based only on 1) substantial contributions to conception and design, or acquisition of data, or analysis and interpretation of data; 2) drafting the article or revising it critically for important intellectual content; 3) final approval of the version to be published. Conditions 1, 2 and 3 must all be met. Acquisition of funding, the collection of data or general supervision of the research group, by themselves, do not justify authorship. All others who contributed to the work who are not authors should be named in the Acknowledgements section.

Committee on Publication Ethics (COPE)

As a member of the Committee on Publication Ethics (COPE), adherence to these submission criteria is considered essential for publication in *Diabetic Medicine*; mandatory fields are included in the online submission process to ensure this. If, at a later stage in the submission process or even after publication, a manuscript or authors are found to have disregarded these criteria, it is the duty of the Editor to report this to COPE. COPE may recommend that

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Early View

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